

Te noho ora me te mate wareware **Living with dementia**



He aratohu mō te hunga kua puta te whakatau
kua pāngia e te mate wareware

A guide for people diagnosed with dementia





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

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

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. Alzheimer's NZ is not liable for any error or omission in this publication, as a result of negligence or otherwise. The persons shown in photographs in this booklet are stock photography models.

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Alzheimers NZ

Email admin@alzheimers.org.nz

Website www.alzheimers.org.nz

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He mea whakamāori nā Piripi Walker

Translation to te reo Māori by Piripi Walker

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He kupu whakataki

Introduction

This booklet is for people who have been diagnosed with dementia. The booklet provides information that will help you continue to live well. There is also essential information for supporters.

Being diagnosed with dementia may have come as a shock to you, as well as your whānau/family and friends. There is a lot you can do to live a healthy life and continue to enjoy life for a long time to come.

This booklet suggests ways to look after yourself including:

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

Every person and whānau is different. You and your whānau will find your own answers to the issues that dementia brings. Information or advice will help along with support from health professionals and others sharing the same experience.



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



More detailed information about many of the topics covered in this booklet can be found at your local Alzheimers organisation or our website **www.alzheimers.org.nz**.



Te mate wareware

Dementia

What is dementia?

Dementia is a term used to describe a group of symptoms (the experience of a physical or mental problem) caused by changes in our brains. Alzheimers disease is the most common form of dementia.

Dementia can affect anyone, and as people get older, the chances of developing dementia increase.

Symptoms depend on the parts of the brain that are affected. The most common symptoms are changes in memory, thinking, behaviour, personality and emotions.

Brain changes can include shrinkage and a build up of abnormal proteins (plaques and tangles) as seen in Alzheimers disease.

Symptoms increase over time for most people as more and more changes to the brain occur.

Dementia is different for everyone – what is experienced, and what you can do. The ability to do tasks, to remember and to understand may change from day to day.

You can stay well with dementia by living a healthy life, being involved with activities you enjoy, and carrying on with routines that work for you as much as possible with help.



Te whakaurutau ki ngā āhuatanga hou **Adjusting to change**

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

Living with dementia can be a big adjustment. Dealing with the changes can be hard. Many people report feeling shock, sadness, frustration, embarrassment, anger and a sense of loss. For some people, getting a diagnosis can be a relief as there is an explanation for problems they, or other people, have been noticing over time.

People with dementia also experience happiness, pleasure and joy. It is normal to feel a range of emotions. 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 Alzheimers or Dementia organisation can give you advice and support and put you in contact with other organisations which can help.

“The one thing that I would really emphasise is that whilst the diagnosis is traumatic, and it is very traumatic... We believe quite generally, you can go on and live a meaningful life with some changes.” – Care partner

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

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.

It is usual to feel distressed for a time while adjusting to the new information and making sense of what it means. These feelings usually diminish with time as you understand what dementia is, and find ways to adjust.

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 and fear

You might feel angry or fearful about the changes you are having to cope with. You might feel angry about having dementia and angry about memory loss.

People also fear losing independence when having trouble with things they used to be able to do easily. It is natural to feel anger and resentment about these things at times.

Frustration

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

Loss and sadness

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

Feelings of hopelessness, sleep problems and loss of enjoyment over weeks and months could mean depression. It is important to talk to your doctor or a counsellor for ways to manage this. Sometimes medication can help.

Embarrassment

It can be embarrassing forgetting a familiar face or not being able to find the right word to express yourself. 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 someone else who has dementia is invaluable. People with dementia often understand better than others as to what it is like to live with dementia. 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 your 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 are still able to do** rather than what you cannot do. Ask for help when you need it to guide and support what you want to do.

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. Join a group and meet others who have dementia to share experiences and ideas for dealing with the condition.

Te oranga wairua – spiritual wellbeing

Spirituality/wairua relates to all that gives meaning or brings peace to our lives. For many people, spiritual faith is an important strength in learning to live with dementia.

Take time to experience what helps you find meaning and a sense of peace. Examples are karakia, maintaining religious involvement, meditation, being in nature, art, music, and spending time with whānau, family and friends.

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. Remember to laugh at some of the unintentional things you may do.

Be kind and patient with yourself

It is alright to forget things. It is alright to have things go out of your head, or not remember where you put stuff. Sometimes it helps to focus on something else for a while, and you will remember later.

These changes are not your fault but are part of an illness. You may just need more time to do or remember things, so be patient with yourself.

Doing one task at a time

Try and only do one task at a time and not get distracted until the task is completed. The changes due to dementia can lead to being easily distracted and tasks not being completed.

Having a purpose

Everyone needs purpose but having dementia can make it difficult to participate in activities and roles which previously brought pleasure to life. Ask for help to carry on usual activities and roles as necessary. There will also be opportunities to share experiences and activities with the support groups offered by Alzheimers and Dementia organisations.





Te whakatakoto mahere

Planning ahead

A dementia diagnosis means making 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 your future.

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

'Capacity' is a legal term that means you are able to understand the information necessary for decision making and anticipate the likely outcomes of decisions. The capacity to communicate decisions is also required.

You are not lacking in capacity just because you have a dementia diagnosis. However, that may happen later on. It's often your doctor who decides when that stage is reached but sometimes it may be another registered health practitioner.

If you're concerned about how you will manage as your dementia progresses, talk to your family, your doctor and/or your local Alzheimers or Dementia organisation staff about 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 your bank or a financial advisor – you can organise your financial affairs for the future and make sure your interests are protected
- talking to your trusted whānau about how they can access your finances for you if you are having difficulties managing your money
- having joint signatures on your financial accounts – this can make it easier for trusted whānau members to support you later.



Enduring Powers of Attorney

It is important to set up an Enduring Powers of Attorney (EPA) as soon as you can. All adults should have EPAs in place.

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 such as such medical decisions and where you live
- one for decisions about your finances (bank accounts, assets, property).

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

Setting up a welfare EPA does not mean it takes effect immediately. You can continue to make your own welfare decisions until the EPA is enacted. This happens when a medical professional has decided you can no longer make good and 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 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 an application will have to be made to the Family Court for a welfare order to make decisions on your behalf. This takes time, might cost your family money and/or might mean that you end up with someone you don't know or would not have chosen looking after your affairs.



Wills

A will is about how you want your estate – your worldly possessions – to be distributed after your death. Like an EPA, a will is only legal if you were capable of understanding 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. It is also important 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 whānau 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 your 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 on various websites – see the last section on **page 54** for some contact details.



Read more about Advanced Care Plans at www.advancecareplanning.org.nz.



Tō tātou tuakiri, ō tātou mōtika

Our identity, our rights

Our identity

You may have to adapt and change how you do things as your dementia progresses but you will always be the same person. Continue to do the things that are important to you. You are still a husband or wife, a grandparent, a friend and a workmate – a diagnosis of dementia does not change that.

We all identify with different cultural groups and communities. These can be related to gender, ethnicity, age, religion, occupation, disability or any other culture with which you relate. Everyone has a cultural identity that is unique and individual to them as well as shared by others.

Acceptance of dementia varies between individuals, whānau and larger communities of people and cultures. There are many ideas and attitudes about dementia. Your ideas may change as you learn more about dementia.

Staying active and connected to your community will help with wellbeing. Your community may have little knowledge about dementia and how people can be supportive. In this case you could talk with your local Alzheimers or Dementia organisation about providing education for your community.

Resources

You can now read the most popular pages on the Alzheimers New Zealand website in te reo Māori. Click the 'mi' button on the top right hand side of the homepage at **www.alzheimers.org.nz**.

The **Mate wareware app** provides information about dementia. See **www.matewareware.co.nz**.

Dementia Australia has translated resources providing advice on many topics in a range of languages at **www.dementia.org.au/languages**. The details about services will be different in New Zealand.

The Moving Pictures project has produced short films with people from diverse communities living in Australia including Hindi, Tamil, Mandarin, Cantonese and Arabic-speaking communities. The films are orientated towards family information needs and cover Detection and Diagnosis, Navigating Care, and the Carer Journey. See **www.movingpictures.org.au**. The details about services will be different in New Zealand.

Alzheimers New Zealand will have resources available on their website in eight Pacific languages from early 2023.

Our rights

As a person with dementia you have rights that cannot be taken away from you. You have the right to be treated with respect, to participate in decisions about your life, to be part of your community, to not be discriminated against and all the other rights that someone without a dementia diagnosis has.

The **Dementia Declaration: Our Lives Matter** on the following page has been developed by the members of the Alzheimers New Zealand Advisory Group, people who have come together to make a difference for all people affected by dementia.

The Group includes people with a diagnosis of dementia and whānau who provide support. If you are keen to become involved in an Alzheimers New Zealand Advisory Group at local or national level or would like to find out more, please call us **04 387 8264**.

Dementia Alliance International is a global selfadvocacy organisation of people with dementia. It works in partnership with organisations such as Alzheimers New Zealand. All people with dementia can join and and get involved with online groups and education activities.



Read more at
www.dementiaallianceinternational.org.

He Whakapuaki mō te Mate Wareware: He Mea Nui Tō Mātou Noho i Te Ao

“E hiahia ana mātou KATOA kia kitea mai e te tangata kē, kia whakanuia, kia kīa he tangata whai painga, kia arohaina mai mō tō mātou āhua tūturu.”

Hei tāngata nō Aotearoa e noho tahi ana me te mate wareware, he kirirarau mātou, ā, he mea nui tō mātou noho i te ao nei. He rite tonu ō mātou tika, ō mātou whiwhinga, haepapa hoki ki ō ngā tāngata katoa. Tā tō mātou Whakapuaki he whakataki i ngā mea e hiahia ana mātou kia noho pai i te ao nei.

Ka eke mātou ki tō mātou tino teitei ina:



Noho tonu te mana mō mātou ki a mātou anō; kua kaha hoki ngā reo tautoko i ā mātou whakatau mō ngā mea hira ki a mātou.



Tōkeke tonu te tautoko i a mātou, te tiaki me te whiwhi mōhiotanga i te wā tonu e tika ana, e hāngai ana hoki ki a mātou; e horaina mai ana i roto i te atawhai e te hunga ngākau pūaroa, he tāngata whai pūkenga tōtika, mātauranga tōtika e arotahi ana ki ō mātou hiahia, he pai tō mātou noho tahi me rātou.



Karapotingia mātou e tēnei kāhui tautoko, he kāhui e ngāwari tonu ai te noho pipiri ki ō mātou whānau, ki ngā hoa, ki ō mātou hoa mahi, me te hunga e noho nei hei mea nui ki a mātou.



Noho mātou i ngā hapori mōhio e awhi nei, e whakaae nei, e mārama pū nei ki a mātou.



Whakauru tonu mātou ki ngā tūranga me ngā mahi whai tikanga, hira hoki ki a mātou.



Tukua ki a mātou tonu ngā mea e hiahia ana mātou ki te noho pai, te tūmataitinga, kia whai moni e pai ai te noho, me ngā āhuatanga kawē i a mātou ki ngā wāhi e hiahia ana mātou ki te haere.



Aroha nuitia mātou; he mea nui tō mātou noho i te ao.

“Ko au tonu ahau.”

He mea tuhituhi tēnei Whakapuaki e te hunga e noho tahi ana me te mate wareware i roto i te Rōpū Tohutohu o Alzheimers New Zealand.



Dementia Declaration: Our Lives Matter

"We ALL want to be seen, valued, appreciated and loved for who we are."

As New Zealanders living with dementia, we are citizens whose lives matter.

We have the same rights, privileges and obligations as everyone else.

Our Declaration sets out what we need to live well.

We live our best possible lives when:



We have control over our lives; we have support to make decisions that are important to us.



We live in knowledgeable communities that include, accept and understand us.



We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable.



We continue to be actively engaged in roles and activities which are meaningful and important to us.



We have the things we need to live well such as housing, privacy, an adequate standard of living, and ways of getting where we need to go.



A circle of support protects our wellbeing, allowing us to maintain strong mutual relationships with our families, whānau, friends, colleagues, and those who are important to us.



We are loved; our presence matters.

"I am still me."

This Declaration was developed by people living with dementia on Alzheimers New Zealand's Advisory Group.



Me whai wāhi, me pukukori

Be involved and active

Staying mentally active and socially involved will help you keep up with your usual activities and help with mental wellbeing. Rather than giving up activities if they are becoming difficult it may be possible to modify the activity.

Breaking an activity down into smaller parts may help. Even if you can't manage all the steps, you may be able to take part in some of them. For example, 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 affects memory and can cause physical problems such as not sleeping well. Work out with your whānau and friends the things you can cope with and focus on one thing at a time.

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 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 keep that up as much as possible.

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

Some people with dementia find being among large groups of people can be overwhelming. Too much noise or activity can cause feelings of anxiety or confusion. 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 important for health and wellbeing. Keeping active keeps us fit and improves muscle control and coordination. Exercise helps blood flow to the brain and may stimulate brain cell growth and survival. Exercise is good both for your body and your brain.

Before you start any exercise programme do talk to your doctor, particularly if you have any other other illnesses or physical challenges or disabilities. Choose activities you enjoy and build them into your daily routine.

Some suggestions include:

- gardening
- swimming
- yoga
- playing with grandchildren
- kapa haka
- walking
- water aerobics
- Tai Chi.

Benefits of exercise

Exercise has many benefits, which means we should all stay as active as possible for as long as possible. Exercise:

- strengthens muscles
- helps with mobility and health problems caused by inactivity
- promotes a good nights sleep
- improves mood and opportunities for social participation
- reduces feelings of stress and depression.

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.



As dementia progresses the possibility of getting lost while walking increases. **Page 48** has suggestions on maintaining safe walking habits.



For further information see the Ministry of Health guidelines on physical activity at www.health.govt.nz/your-health/healthy-living/food-activity-and-sleep/physical-activity.

Mental exercise

Learning new things and doing a variety of activities are really good for your brain. Both help you feel better. Keeping your brain active helps you 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.

Cognitive Simulation Therapy (CST) courses

Cognitive Simulation Therapy courses are delivered in a group format over several weeks. The course sessions are aimed to be an enjoyable social and learning time. Course sessions include discussing life and current events, art, music, and physical games.

There is evidence about the effectiveness of group CST – the sessions have positive impact on mood, improved memory, concentration and quality of life. Find out from your local Alzheimer or Dementia organisation about courses in your region.

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.





Te mahi Working

Getting a diagnosis of dementia does not mean you need to give up work immediately. 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 your 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 or Dementia 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 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 coworkers. 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 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.

Te taraiwa waka

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 doctor. 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, whānau 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. Plan ahead for this. 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 some 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 there are opportunities for exercise and meeting people.

Find ways to get about by:

- asking a family member or friend to give you a lift
- using buses, trains or taxis
- walking – also good for exercise
- using 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: **www.nzta.govt.nz/resources/total-mobility-scheme**. Your local Alzheimers organisation (**0800 004 001**) or Dementia organisation can help you to access this scheme.



For more information on life after driving visit Waka Kotahi New Zealand Transport Agency (NZTA) at **www.nzta.govt.nz/driver-licences/life-after-driving**.



For more helpful information on dementia and driving visit the Waka Kotahi New Zealand Transport Agency (NZTA) at **www.nzta.govt.nz/driver-licences/getting-a-licence/medical-requirements/dementia-and-driving**.



Te noho takitahi

Living alone

If you live alone, you may be able to continue to do so for some time after getting your diagnosis.

Here are some ideas that might help you. They are also useful if you live with other people.

Ask for help

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

Whānau 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 whānau 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.



Many people living with dementia make changes to their home and wider environment to support their independence. Check the tips on **page 46**.

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 whānau, friends or a trusted neighbour.

Night light

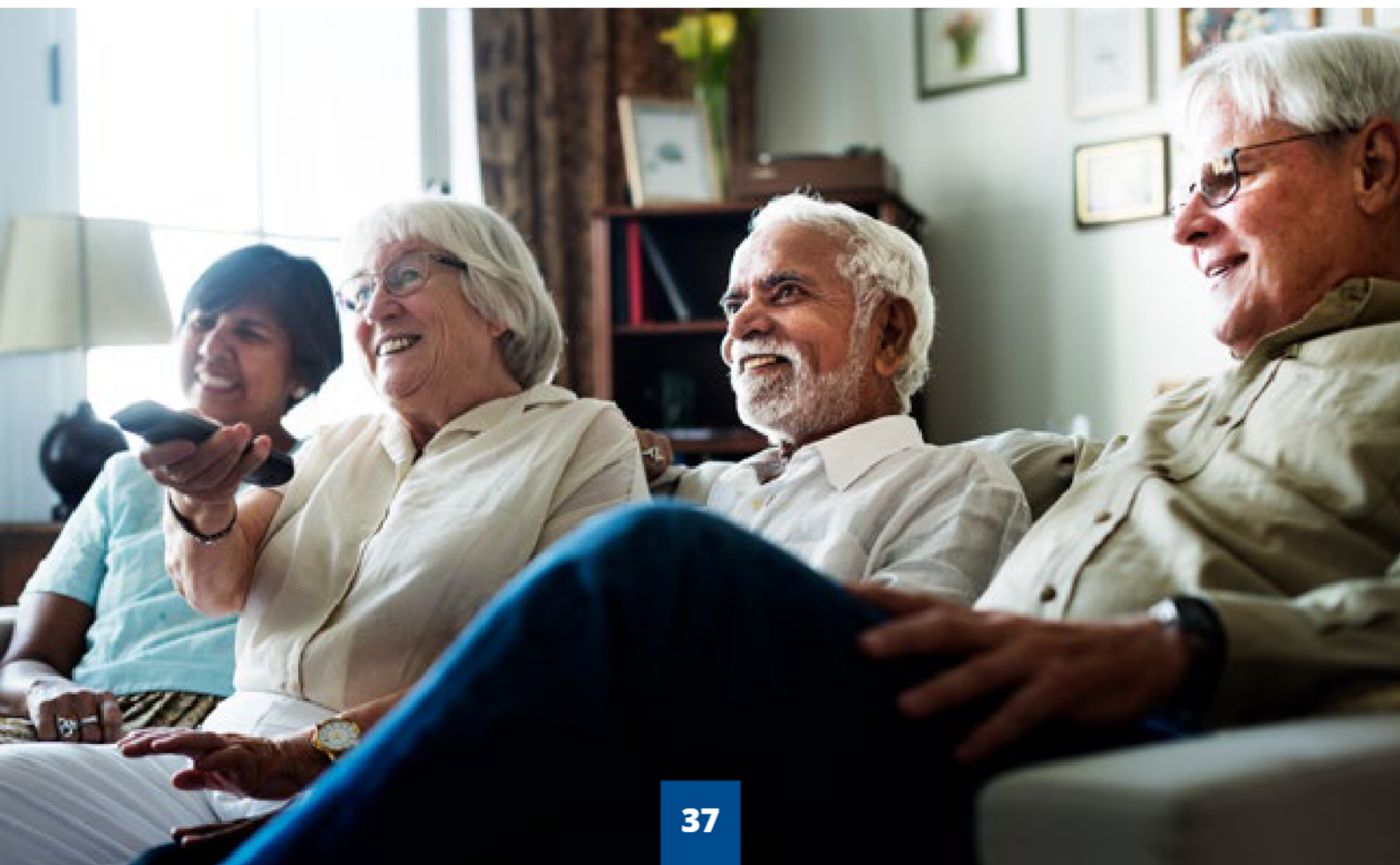
If leaving a light on at night disturbs your sleep, a sensor light inside that automatically turns on when you move around might be a better alternative.

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 branch by phoning **0800 004 001** or visiting Dementia New Zealand at **www.dementia.nz** and tell them you would like to join a support group for people with dementia.





Te noho ora me ō tohu

Managing your symptoms

Each person with dementia has different symptoms to manage. Memory loss is the most common symptom of dementia. Often it is 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.

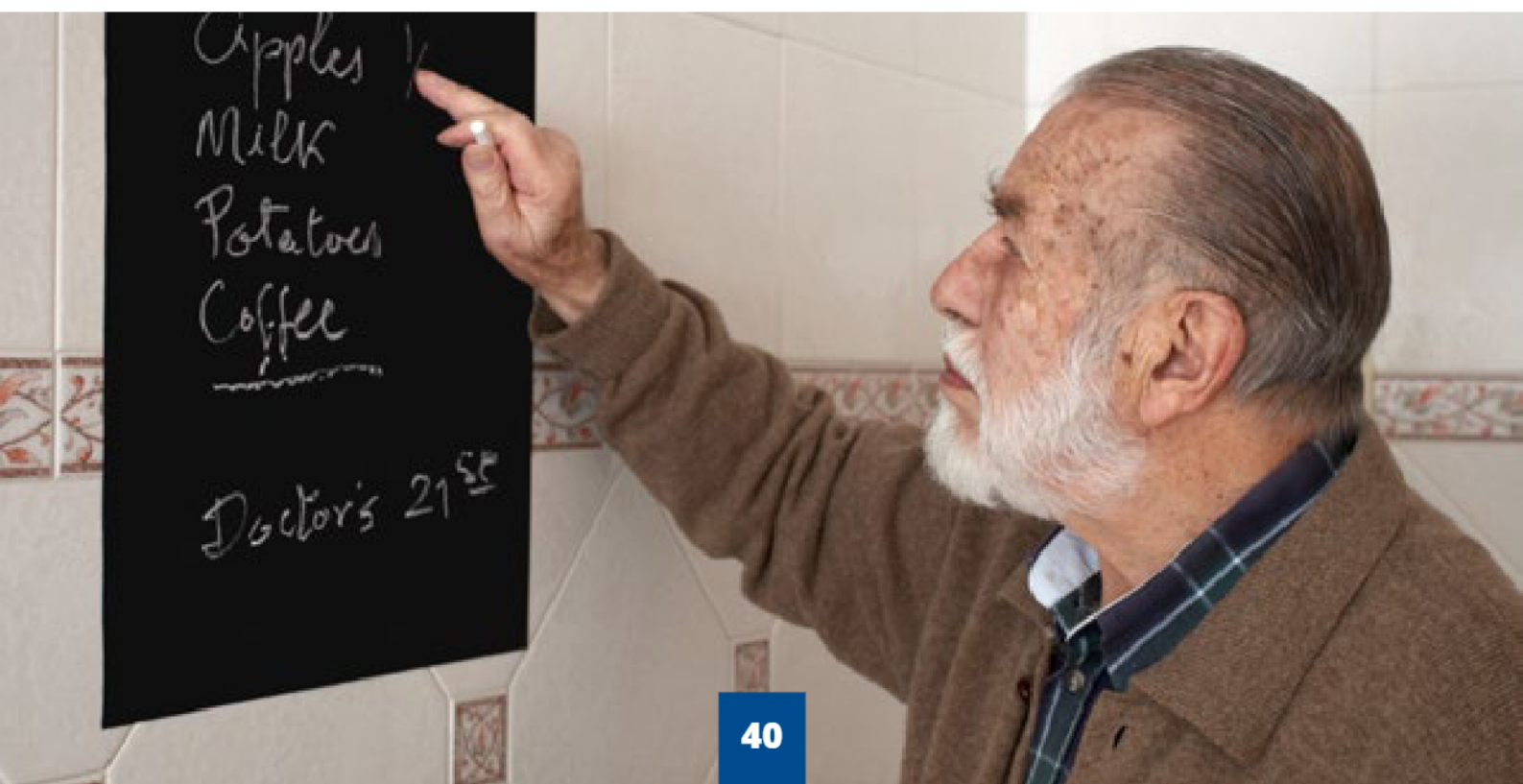
You might want to keep a note of:

- 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
- 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 whānau 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.



Te mate pōuri me te mate wareware

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
- not being able to go out alone
- not being able to do the things previously enjoyed
- not being able to do everyday tasks
- feeling anxious or agitated
- 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.
- There can be problems communicating with doctors and people providing care, or there may be difficulties in describing symptoms.

Am I depressed?

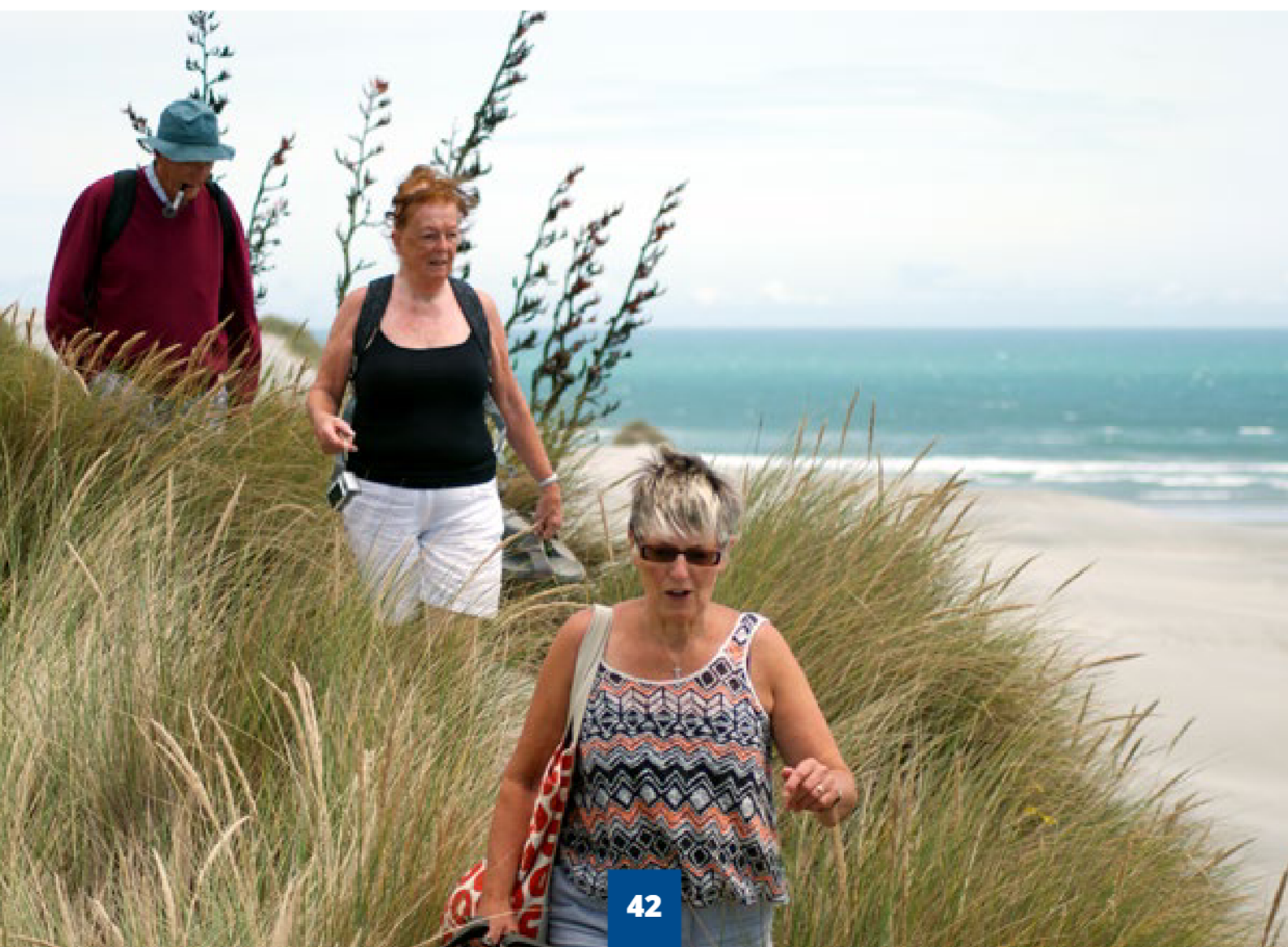
Depression can be even more difficult to diagnose in yourself when you also have dementia.

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

People with dementia talk about how being out and about in green spaces is good for mental health.



See Evidence at a Glance – Out and about in Green Spaces at alzheimers.org.nz/about-dementia/booklets-and-factsheets for more information.



Ngā āhuatanga noho o ia rā

Everyday life

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
- having routines
- 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 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
- 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.

Being able to communicate helps keep you socially connected. 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.

Ask your primary care provider for a referral to a Speech-Language Therapist.

A speech and language therapist works with people to improve their communication and swallowing abilities. They aim to maintain the person's quality of life for as long as possible.

They can assess thinking skills which affect communication e.g. memory, attention. They may also talk to the people you communicate with the most, so those people have the skills to help you keep conversing.

They can work with you to practice remembering important information, create conversation aids e.g. memory books, and give friends and family/whānau training on keeping communication going.

The speech and language therapist can also assess your swallowing abilities and put strategies in place that make the swallow safer or more comfortable.

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.
- 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.

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

General approach

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

Changes in the home

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

When out and about

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

Managing finance

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

Offering reassurance to family

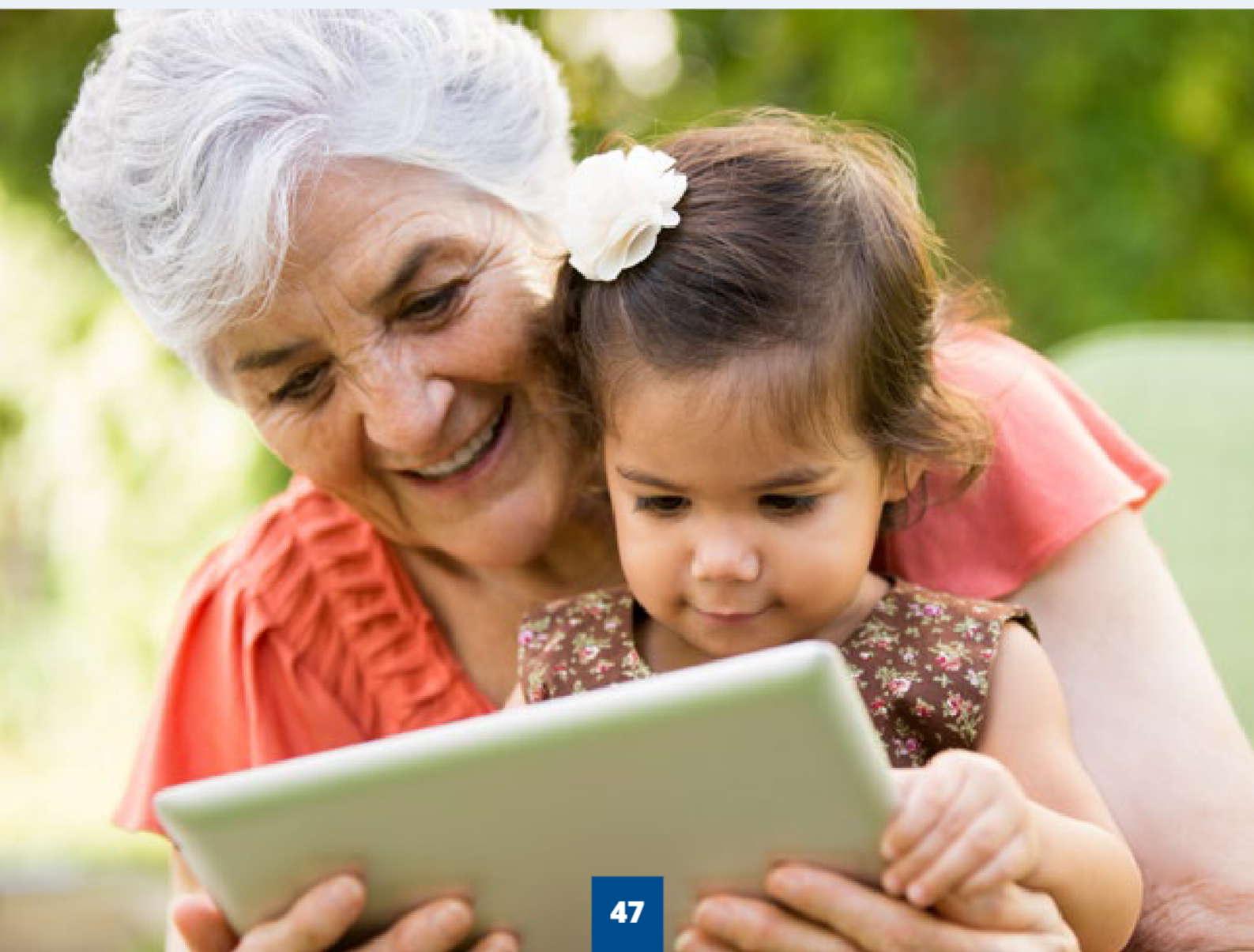
- Install a medical alarm to be able to call for help, if needed
- Have a GPS tracker so care partners can find you if you are lost.

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

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



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



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.

Here are some suggestions to help you keep the confidence to go out:

- Have a whānau discussion about how to support your ability to get out and about. This can be part of advanced support planning after the diagnosis of dementia is made.
- 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.
- Consider a locator device such as a mobile phone with a GPS function, or specialised devices using GPS or radio frequencies. Your local Alzheimers or Dementia organisation can provide information about available 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.



Check out the Safer Walking NZ Te Ara Pai website **saferwalking.nz** for tips and strategies to support safer walking. These include suggestions for changes to the home environment, as well as technology that can be introduced to help you feel safe and be able to be located if required.

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
- keeping socially connected
- eating a balanced diet
- making sure you have time to relax each day
- resting when you are tired
- getting a good nights sleep – if you have sleep problems see Health Navigator at **www.healthnavigator.org.nz/health-a-z/s/sleep-problems**
- getting hearing loss checked and wearing a hearing aid if needed – information at **www.audiology.org.nz/for-the-public**
- limiting how much alcohol you drink
- 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. See Health Navigator at **www.healthnavigator.org.nz/health-a-z/m/medicines-tips-to-remember-to-take-them** for tips on remembering to take your medicine
- 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.

Te kai, te inu me te oranga roro

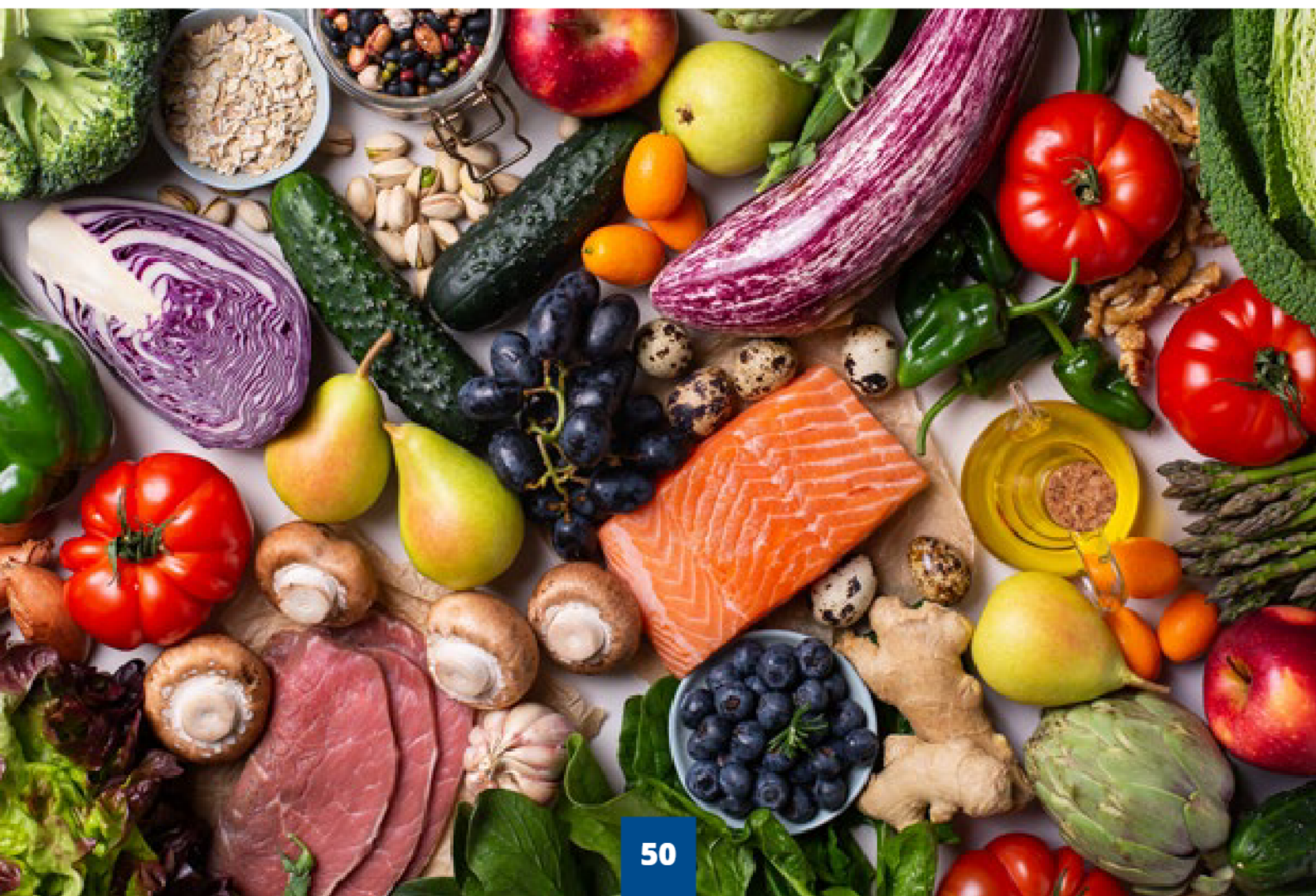
Eating, drinking and brain health

Our body and brain rely on food for fuel. A healthy, balanced diet keeps us functioning well.

More studies are needed into the benefits of specific foods or supplements. We do know to avoid eating lots of fatty and processed foods which are high in saturated fat, sugar and/or salt because of the association with a higher risk of heart disease.



Eating a Mediterranean-style diet is a good way of keeping to a healthy diet. Check this website for more information:
www.healthinfo.org.nz/index.htm?The-Mediterranean-diet.htm



Remember, what is good for the heart is good for the brain.

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

Healthy eating

- 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)
- Eat lean protein – fish, beans and chicken
- Have low-fat dairy products
- Drink plenty of water.

Foods to limit

- Limit red meat
- 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
- Limit alcohol.



He tautoko kia noho pai me te mate wareware

Support to live with dementia

There's support available for you and those who support you. Your local Alzheimers NZ or Dementia 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 or Dementia 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 or dementia organisation or to a whānau member or friend.

Mōhiohio whānui me te tautoko

General information and support

Alzheimers and dementia organisations

Alzheimers New Zealand

www.alzheimers.org.nz | 0800 004 001

Dementia New Zealand

www.dementia.nz

Enduring Power of Attorney (EPA)/Wills

Family Court

www.justice.govt.nz/family

Law Society

www.lawsociety.org.nz

Ministry of Social Development

www.msd.govt.nz/epa

Public Trust

www.publictrust.co.nz

Other useful contacts

Age Concern

www.ageconcern.org.nz

Health and Disability Commissioner

www.hdc.org.nz

Senior Line

www.seniorline.org.nz

Citizens Advice Bureau

www.cab.org.nz

Carers New Zealand

www.carers.net.nz

Alzheimers New Zealand web page “Where to go to for help”

alzheimers.org.nz/get-support/where-to-go-for-help

Driving

Waka Kotahi New Zealand Transport Agency

www.nzta.govt.nz/driver-licences/getting-a-licence/medical-requirements

Advance care planning and end of life care

Advance Care Planning Co-operative

www.advancecareplanning.org.nz

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



Alzheimers NZ
0800 004 001
www.alzheimers.org.nz
admin@alzheimers.org.nz