

The dementia and driving toolkit

Putea utu mo te mate ware ware
me te taraiwa
Marlborough



Kia Ora, Welcome

This booklet is for any driver who is living with dementia. It will help you to know what to expect and how to plan.

We hope you will share this booklet with the people who support you.

This booklet has four chapters:

- 1. How dementia affects driving**
- 2. How to prepare for retirement from driving**
- 3. How to know when it's time to retire from driving**
- 4. Coping with loss**

Chapter 1

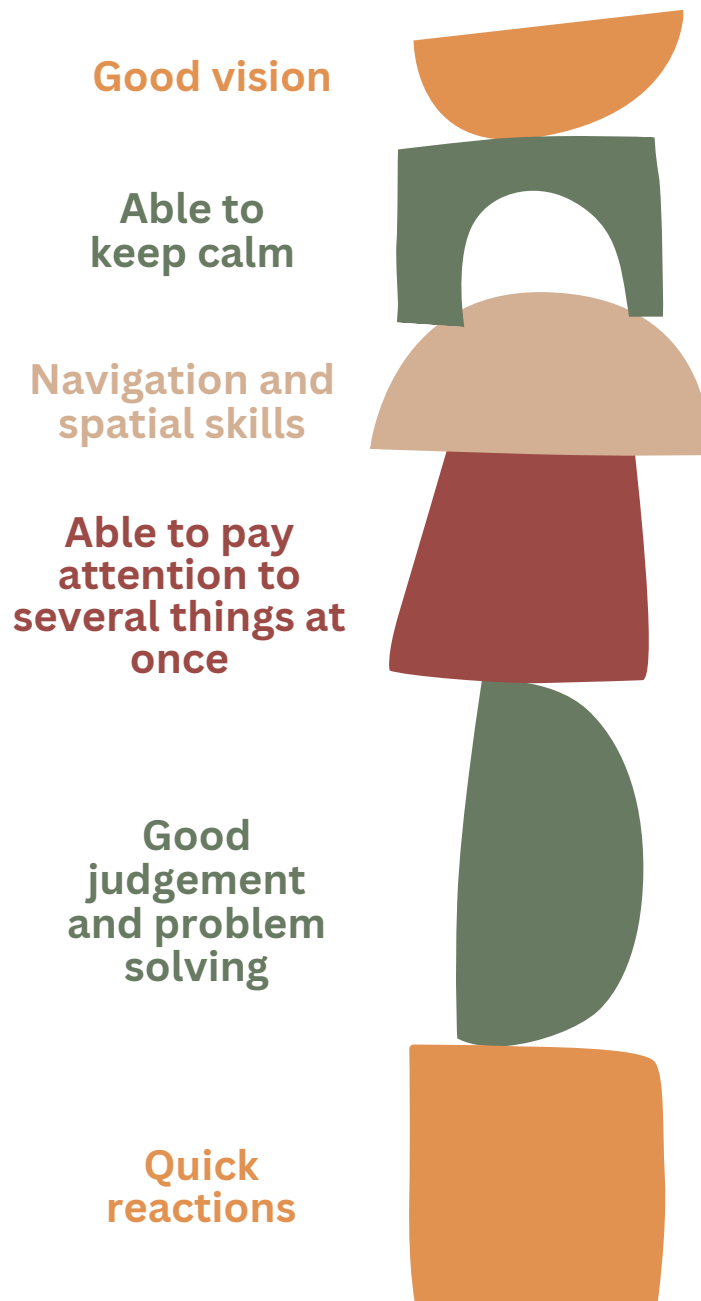
How dementia affects driving



Why does dementia affect driving?

There are many health conditions that can impact on driving abilities. Dementia is one of them.

To drive safely, we need a range of brain abilities. We can think of these as the building blocks of driving. If any one of these abilities becomes impaired, then our driving becomes unsafe. Dementia can affect these brain abilities.



But I've been driving for years, won't I be ok?

Driving can feel automatic for an experienced driver. It's easy to forget how complex driving is.

01

At the **basic** level there are the physical parts of driving. They become automatic after many years of driving. We can steer and brake without thinking too much about it.

02

At the second level, there are **tactical** abilities. This is your ability to do actions like changing lanes before you turn, slowing in response to traffic in front of you, etc.

03

Finally, at the top level, there are **strategic abilities**. This refers to your ability to make smart decisions when unexpected situations occur.

While all three skills levels are important for driving, the strategic level is often affected first when we have dementia.

*With hindsight you see things differently ...
There's a lot more thinking involved in driving
than you are aware of.*

What are guidelines in New Zealand?

By law, the New Zealand Transport Agency (Waka Kotahi) must ensure that all drivers are medically fit and can drive safely.

The Australian and New Zealand Society of Geriatric Medicine says:

- **Some people with mild dementia may be able to continue driving for a limited period of time**

Being fit to drive

Mature adults with many years of experience are generally good drivers. They have excellent basic skills because they have driven for so long. They tend to drive more carefully.

However, being “fit to drive” means having all the capabilities needed to be safe on the road even when unexpected things happen. Fitness to drive is affected by dementia, even for good drivers.

As dementia progresses, it affects driving skills more. The risk of having an accident increases. For many people, this happens without them realising it.

People living with dementia will eventually have to retire from driving.

Let your insurance company know

It is very important that you tell your car insurance company about your diagnosis of dementia.

Your insurance policy says that you must tell your insurer about anything that affects your insurance. If you don't tell your insurance company about your dementia diagnosis, they may refuse to pay if you are involved in an accident.

Taking control

Realising that your driving days may be limited can come as a shock.

Driving is a symbol of freedom and independence. You can go where you want when you want. Driving may be your go-to way of getting around. In fact New Zealand is one of the most car-dependent countries in the world. Some people have told us that the thought of losing their licence is like losing an arm! But, despite our attachments to cars, there will come a time when it's wiser to give up driving.

Thinking about retiring from driving in advance could save you from added stress when the time comes. It is never too soon to start! You can start right here with this booklet.

Chapter 2

How to prepare for retirement from driving



Why start planning now?

Planning for retirement from driving will make the transition much easier, just like planning retirement from work.

The best plan is to gradually limit your driving and figure out other transport options that work for you. It's always a good idea to involve those who care about you when planning.

Taking a gradual approach has many advantages.

- You avoid sudden changes.
- You have time to get used to other transport options.
- You can have a plan to keep doing the things you enjoy.
- You can be more in control.

It can be really helpful to talk about driving and planning for the future with an Alzheimers South Canterbury Dementia Advisor, or your Health Improvement Practitioner at your General Practice.

I actually chose to stop driving. Because I'd chosen, it actually didn't cause me any stress. I had made that decision myself over a few years so that it wasn't just suddenly "you're not allowed to drive".

Limit your driving

We can avoid situations that are more challenging to reduce the risk of accidents.

Do



Do drive routes you are familiar with



Do try to keep your trips short



Do allow plenty of time to get where you are going



Do travel with another adult

Don't



Don't drive if you feel tired, stressed, or upset.



Don't drive at busy times



Don't drive at night or in bad weather



Don't drive with distractions like the radio.

Thinking about costs

You might be worried about the costs of other transport options if you stop driving. You may be surprised by how much it costs to run a car. There are also schemes that can reduce the cost of some other transport options.

The cost of a car

Owning a car can be much more expensive than we realize.

The AA has figured out the average cost of running a new small petrol car.



You need to pay for insurance, a warrant of fitness, and registration. There is also the cost of repairs, maintenance, and petrol. These cost add up to around \$8,000 a year. That's \$22 a day.

When you retire from driving, you won't have these costs. You may even decide to sell your car. You can use the money you save to pay for other ways of getting out and about. It might even be cheaper in the long run.

Total Mobility Card

People living with dementia are eligible for the 'Total Mobility Card'. The card pays for 75% of the cost of using a taxi or companion transport service, up to a limit for each ride.



This can make a big difference to the affordability of using taxi or companion transport services!

These organisations can help you apply for the card and give you local information.

- Alzheimers South Canterbury (03) 687 7583
- Age Concern South Canterbury (03) 687 7581.

Gold card

If you are aged 65 or over, you are able to get a SuperGold card. With your SuperGold card, you can travel free on public transport between 9am-3pm and after 6.30pm on weekdays, and all weekends and public holidays.

Metro Timaru offers on-demand transport through the MyWay app or by booking through your medical practice, dentist, pharmacy, bank, the information centre, and some supermarkets and shops.

A new Motu Move card for public transport will be introduced in 2025 or 2026

Total mobility card. It's for taxis or whatever. You just show that when you get a taxi and the price comes down. I've got one driver. I'll call him, and he says 'I'll be there in two minutes'.

Thinking about options

Driving is very convenient, but it's not the only way to get to the activities and places that are important to you. Here are some options to think about.



Rides with people you know

Who might be willing to provide a ride? It can be a good idea to ask a few different people to spread out who you are getting help from.



Taxis

Is there a taxi service where you live? Taxi fares for approved companies can be discounted with the Total Mobility Card. If you find a driver you trust, you may be able to ask for the same driver again.



Companion Drivers

Companion driving services can not only drive you, they can provide assistance and company if you want it. Costs can be discounted with the Total Mobility Card for approved services. Local providers are:

- Timaru: Driving Miss Daisy 0800 948 432
- Waimate: There is the Waimate Community Vehicle Trusts with volunteer drivers [689 6226](tel:6896226)



Walking and biking

Can you safely walk or bike to some of the places you want to go? Are there familiar routes that avoid traffic?



Public transport

Are you near a bus or train stop? Does it go near where you want to go? If you haven't taken public transport for a while, you could try it out with a friend or family member.



Home services

Are there mobile services or delivery services in your area that would save you some trips? You may be able to have a friend, family, or whānau member help order groceries online to be delivered. Some hairdressers, vets, and health professionals will come to your house. Some pharmacies, supermarkets, and libraries will deliver.



Health shuttles

The Waka Ora Health Shuttle is a koha (donation) based community service, delivered by volunteers. The shuttle transports people to health and wellbeing related appointments, and then brings them home again. You can contact them on 0800 103 046.

Thinking about getting home safely

It can be reassuring to take a backup when you are out on your own, just in case you get lost.



You could take a mobile phone with your support person's number programmed in.



You could take an identification card or bracelet with your support person's contact details on it, so that a helper can call.



There are a number of technology options that can safely locate you if you get lost. These include

- Applications for your mobile phone
- GPS devices
- Blue tooth devices like Airtag, TilePro, or SmartTag
- Wandersearch radio frequency transmitter devices

You can find out more on the Safer Walking website <https://saferwalking.nz/technology/>

Try out other options now

Getting comfortable with different ways of getting around while you are still driving can help you stay active and engaged later.

Test one alternative method of transport and see how it works for you. Don't love it? Wait a while and try another. The key is to start early, while it's still an option and not a necessity. That way, you're in control from the start.



Step One

Think about where and why you drive. Discuss the places you enjoy going to and the places you need to reach.



Step Two

Talk over different ways you could get to these places without driving yourself.



Step Three

Pick some different travel options to try out now. Write your decision on the next page.

What's your decision?

Pick at least one idea to try out this month.

Instead of driving to:

I will try:

Instead of driving to:

I will try:

Instead of driving to:

I will try:

Instead of driving to:

I will try:

Instead of driving to:

I will try:

Chapter 3

How to know when it's time to retire from driving



Timing



Driving provides independence, convenience, and enjoyment. This must be weighed against the risk to yourself and other road users if you continue to drive when it is no longer safe.

As soon as you have a dementia diagnosis, it is important to keep checking whether your driving is safe.

If a health professional instructs you to stop driving, the law says that you must stop driving immediately. However many people make their own decisions to seek a driving assessment or to retire from driving before they 'lose their licence'.

The family say they are so proud he got an assessment and stopped driving. It's so important. They say "Dad we love that you always put other people first".

Top tip

Get feedback on your driving

People are often unaware of how dementia affects their own driving.

It can be hard to accept, but friends and family or professional assessments may notice changes in your driving skills before you do.



Kate has dementia. She was stunned when a driving assessment found that she wasn't safe to drive. Kate compares the effects of driving under the influence of dementia to driving under the influence of alcohol.

We know that alcohol can impair a driver's judgement, attention, and reaction times. But alcohol also makes it harder for a driver to judge when they are unsafe to drive.

In the same way, dementia can impair a driver's judgement, attention, and reaction times. Dementia can also make it harder for a driver to recognise that their driving is impaired. We need friends, family, and authorities to help prevent an accident.

Talk with friends, whānau, and family



Family, friends, and whānau may be the people who know your driving best. They are often the first to notice changes in driving. Here are some ideas for being proactive.

- Ask someone you trust to give you an honest opinion about your driving. The questionnaire on the next page can help them think about your driving.
- Think about who you trust to raise any concerns and help you retire from driving when the time comes. You can use the "Agreement with my family about driving" on page 23 to formalize your agreement.

My husband got tooted at twice because of trouble merging into traffic. He came home and asked "Am I getting worse?"

Warning signs

This list was made by a person living with dementia from his own experience and talking with others.

If you, your family, or whānau notice some of these warning signs, talk with your GP or arrange a driving assessment.

- | | |
|---|---|
| <input type="checkbox"/> Hitting the mailbox when entering a drive. | <input type="checkbox"/> Having trouble reading road signs. |
| <input type="checkbox"/> Hitting the kerb when parking or turning. | <input type="checkbox"/> Taking longer on routine regular trips. |
| <input type="checkbox"/> Being involved in “near misses”. | <input type="checkbox"/> Going too slow or too fast for that road. |
| <input type="checkbox"/> Getting tickets for traffic offences. | <input type="checkbox"/> Forgetting where you parked the car. |
| <input type="checkbox"/> Other drivers honking or gesturing at you. | <input type="checkbox"/> Not slowing for pedestrians. |
| <input type="checkbox"/> Getting lost while driving. | <input type="checkbox"/> Problems with driving in the dark and rain. |
| <input type="checkbox"/> Having problems with right turns across traffic. | <input type="checkbox"/> Passengers being nervous and pointing out dangers. |
| <input type="checkbox"/> Misjudging the speed of other traffic. | <input type="checkbox"/> People refusing to be your passenger. |
| <input type="checkbox"/> Getting angry at other drivers. | <input type="checkbox"/> Forgetting headlights or seat belt. |
| <input type="checkbox"/> Getting bewildered and confused. | <input type="checkbox"/> Forgetting to fill up fuel or putting the wrong fuel in. |

Agreement with my family about driving

This page can help you record your choices for the future. Suggestion: Give copies to your family and your doctor.

To my family:

I realize that the changes caused by dementia process will affect my ability to drive safely at some point. This statement is an expression of my wishes.

- I want to drive as long as it is safe for me to do so.
- I want my family to help me explore other forms of transport, to help me to keep doing the things that are important to me.
- When it is not reasonable or safe for me to drive, I want this person to raise the issue with me:

_____ (Person's name)

- If not safe for me to drive, I want my family to take any necessary steps to make sure that I stop driving, while maintaining my dignity.

Signed _____ Today's date _____

Talk with your health team



Your GP, general practice team, or whare hauora team can help by:

- Providing support by talking to you and sharing ideas.
- Giving you a 'driving check-up' and discussing the results and recommendations with you.
- Possibly referring you to a specialized driving assessment if the doctor is unsure about your driving fitness.

When will my GP practice talk about driving?

It's recommended to talk about driving often:

- When you first get your diagnosis of dementia
- As part of your regular review every 6-12 months
- When you need to get a medical certificate to renew your driver's licence at age 75, 80, and every two years after
- If your condition changes.

How will they assess if I am safe to drive?

The doctor or nurse will ask questions about your medical history, complete a physical examination, and check your memory and thinking process. They will consider any changes in your thinking, physical abilities, health, and eyesight that might impact on driving.

Is it a good idea to take a support person?

Yes. A support person can help you cope with challenging conversations, help share and remember information, and help in practical ways. Let your doctor or nurse know that you want to involve your support person in conversations about your dementia. This can help clarify your privacy wishes down the track.

What can my health professional decide?



You are able to continue to drive for the time being



You are able to continue driving but limits are put on your licence, for example only driving during daylight.



It is unclear whether you are safe to drive. Your need to have an on-road assessment.



It is no longer safe or legal for you to drive. You must stop immediately.

Assessment with an occupational therapist



Driving assessors can go for a drive with you to assess whether you are still safe to drive. A medical driving assessment with an occupational therapist (OT) is the most reliable way to determine whether you can still drive safely.

What happens at a medical driving assessment?

There are two parts of the assessment. The whole process may take 2-3 hours. It might be split into two appointments a week apart.

- The occupational therapist will ask you about your medical and driving history. They will give you some tasks to do. Some tests may be on a computer tablet. They will use special equipment to test your reaction time, strength, and eyesight.
If the tests show you are unsafe to drive, the assessment may end there.
- The second part of the assessment is a road test. This is generally in a car provided by the assessment centre. There will be a driving instructor beside you and an occupational therapist in the back. Your support person will not come with you.
- At the end of the assessment, the assessors will explain what they have found. A report will be sent to your GP.

Booking a test

You will be referred by your GP. Driving assessments are conducted through the Laura Ferguson Brain Injury Trust. Once your GP has made a referral, you can call them on (03) 335 0541 for further details and their charges for medical driving assessments.

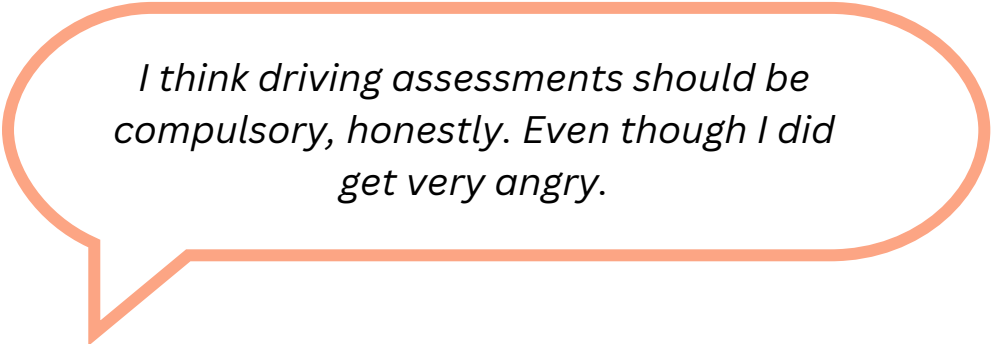
Going to the test

It is a good idea to go with a support person. If the assessment finds that you are unable to drive safely you won't be able to drive yourself home.

Remember to bring your driver's license and the glasses you use for driving.

Being as relaxed as possible helps us to do our best. Here are some tips to consider.

- Arrive in plenty of time.
- Before the assessment go for a short walk or chat with your support person to relax.
- Turn off your mobile phone to avoid distractions.
- Tell the assessor if you have hearing difficulties.
- Ask for clarification of instructions.



I think driving assessments should be compulsory, honestly. Even though I did get very angry.

NZTA (Waka Kotahi) On-road Safety Test



Your doctor may refer you for a New Zealand Transport Agency (Waka Kotahi) On-Road Safety Test. Your doctor will give you a medical certificate to take to the test.

What is an On-Road Safety Test?

The On-Road Safety Test checks that you are following the road rules and driving safely. During the test, you go for a drive in your own car with a testing officer. The testing officer is not a health professional, so this test is not as specialised as a medical driving assessment with an occupational therapist.

Booking a test

You can book the test through the AA, VINZ, or VTNZ.

How can you prepare?

There is a useful guide to the on-road safety test. You can ask when you book your test or download it online

www.nzta.govt.nz/assets/resources/on-road-safety-test

I went to a person who sat beside me while we were driving, and she watched what I was doing and then marked me on everything. I thought it was useful because I felt safe to drive then.

Chapter 4

Coping with a sudden loss



When you lose your licence

It's normal to be upset with losing the ability to drive—it's a big change. You may grieve the loss of independence or the enjoyment you got from driving. It'll take time to work through those feelings. Know that it's possible to move forward and continue to enjoy life.

- Talk to family, whānau, friends or other people about how you are feeling. It's ok to ask for support.
- Remember that many people retire from driving for health reasons, you are not alone.
- Look after yourself. When you feel healthy, you're better able to cope emotionally. Do things you enjoy to care for yourself.
- Sometimes grief can lead to depression. You may feel hopeless, angry, or miserable all the time. You may not enjoy things anymore. If you feel like this over time, it's important to get professional support. You can talk to your GP or free call 1737.

It was like grieving. It's a big thing in your life. I've gotten over it, really. Because I do a lot. I now do a lot of walking to get out and do my best to do my shopping in bits and pieces and things like that. And with the Total Mobility card, of course, with taxi service. It's taken me 18 months. But I've realised now that I'm no worse off. In fact, I'm probably better off, probably not paying as much.

What grief can feel like

Denial

You refuse to accept the facts:
I can keep driving, I drive as well as ever.



ANGER

*It's not fair!
It's their fault I lost my licence.*



BARGAINING

You try to find a way out:
I'll drive more carefully if I can keep my licence.



DEPRESSION

You feel sad and helpless
My life is over.

ACCEPTANCE

You finally find the way forward.
*I don't want to hurt someone if I'm unsafe to drive.
If you help me with the bus schedule, I'll give it a try.*

Practical questions

Do I have to stop immediately?

When a health professional has told you to stop driving, you must stop immediately. Driving without a valid licence is an offence under the Land Transport Act.

But I only drive short distances, so why worry?

Most accidents occur close to home, like trips to the supermarket or shops. This is why even taking short trips to familiar places can be dangerous.

Can I get a second opinion?

You can get a second opinion from another health professional. The Land Transport Act legally requires you to tell the new health professional about your pre-existing medical conditions and failed test.

What can I use for identification Instead of my licence?

The Kiwi Access Card is a Government-recognised form of photo ID. You can pick up the application from most NZ Post or AA Centres. You can also download a form online: <https://kiwiaccess.co.nz/>





Moving forward

At some point, it is necessary to digest our new reality and realise that things can't go back to the way they were.

Adjusting to retirement from driving can take some time. To adapt, we may make practical changes and learn new skills, such as booking drivers in advance.

- If you haven't already, look over the transport options on pages 13-15. Think about what might work for you.
- Alzheimers South Canterbury can offer support. They can be contacted by calling (03) 687 7583 .
- A Health Improvement Practitioner can help you through the adjustment of retiring from driving. Check to see if your General Practice has this service available.
- Age Concern provides information and insights about how to stay mobile in a "Life without a car" booklet. You can call Age Concern South Canterbury on (03) 687 7581.

Remember, it is important to keep active and connected with other people. Retiring from driving does not mean that you have to give up what is important to you.

He toka tu moana ara he toa rongonui.
A rough sea can still be navigated.

Acknowledgements

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- Anne Dickerson: *Plan for the road ahead* (East Carolina University).
- Mark Rappaport and Gary Nagalie: *Driving and dementia roadmap*. (Team 16 of the Canadian Consortium on Neurodegeneration in Aging).
- Anthony Levinson: *Changing Gears- Making a plan for retiring from driving* (McMaster University)
- John Carmody and team: *Dementia and driving a decision aid*. (Dementia Training Australia and University of Wollongong.)
- Dementia Australia Victoria. *Changed conditions ahead: Dementia and Driving Guide for Families and Carers*
- Age Concern NZ: *Life without a car*
- New Zealand Transport Agency: *Getting around as a senior*

Notes

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Notes

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are colored in a sequence from top to bottom: pink, light blue, light green, and teal. There are four lines of each color, totaling sixteen lines across the page. The lines are evenly spaced and extend across the full width of the paper.