



**Dementia  
Friendly  
Communities**



**Toolkit**

## Why are Dementia-friendly communities important?

New Zealand's population is ageing. Twenty-five percent of our population will soon be over 65. The number of Kiwis with dementia is growing rapidly. Almost 70,000 of us are living with dementia today, and this is predicted to rise to 170,000 by 2050. Eighty percent of us know or have known someone with dementia. It is one of New Zealand's biggest and growing social and health issues, and there is still stigma, fear and misunderstanding associated with dementia.



Seventy percent of Kiwis with dementia are living in the community. Just like any other Kiwis, people living with dementia want to lead full and active lives doing the things they enjoy in their communities. While many assume that a person with dementia will be in secure care, the fact is that most people living with dementia live in the community and spend their time just as everyone else does, doing all the things that we all want to do and enjoy. That is why improving and enhancing the communities that we live in to make them easier and safer to live in for people with dementia is the right thing to do.

People living with dementia have the same rights as anyone else to maintain their independence and quality of life for as long as possible. Dementia impacts individuals, families and communities. The stigma and progression of dementia, as well as the presence of physical and social barriers, can make daily life and ordinary routines more difficult. This can lead to withdrawal from familiar places and people, resulting in isolation, inactivity, decreased independence and reduced quality of life. Loneliness and social isolation, depression and physical inactivity are all potentially modifiable [risk factors](#) for

dementia in later life and can be targeted in dementia-friendly work. That is why creating dementia-friendly communities is so important.

## Dementia-friendly communities

A dementia-friendly community is one where people living with dementia are supported to be engaged in community life, where they can live, play, shop and work, engaging in activities and events that provide a sense of belonging, purpose and safety as they choose, just like the rest of us. Most of us want to stay in our own homes and communities as we age, and this is no different for people with dementia.

Everyone does better when they live in a community that is inclusive and accepting – a community that supports them to be active and participate. This is no different for someone living with dementia. Dementia-friendly communities set out to create safe, supportive communities that understand and seek to address things they can change and improve for people with dementia.

In a dementia-friendly community, people living with dementia can maintain their social networks, continue to attend community events and take part in community and recreational activities, conduct their affairs, shop, socialise and eat out, volunteer and work as they wish. They can:

- access programmes, resources and services designed with their needs in mind and provided by people who respect and understand their needs
- have control over the decisions that impact their lives
- take part in the community and its environments safely and without barriers – this includes being able to get out and about and navigate safely and being able to access and maintain physical, social and wellbeing activities
- access housing and support to live as they choose for as long as possible
- feel a sense of belonging, independence, safety and value in social and community settings.

These aspects of community are important in age-friendly work too, but if the specific needs of people with dementia are not addressed, barriers to participation can remain unaddressed. Dementia-friendly communities exhibit a high level of public awareness and understanding so that people living with dementia are encouraged to seek help and are supported in the community. Dementia-friendly communities adapt their facilities, infrastructure,

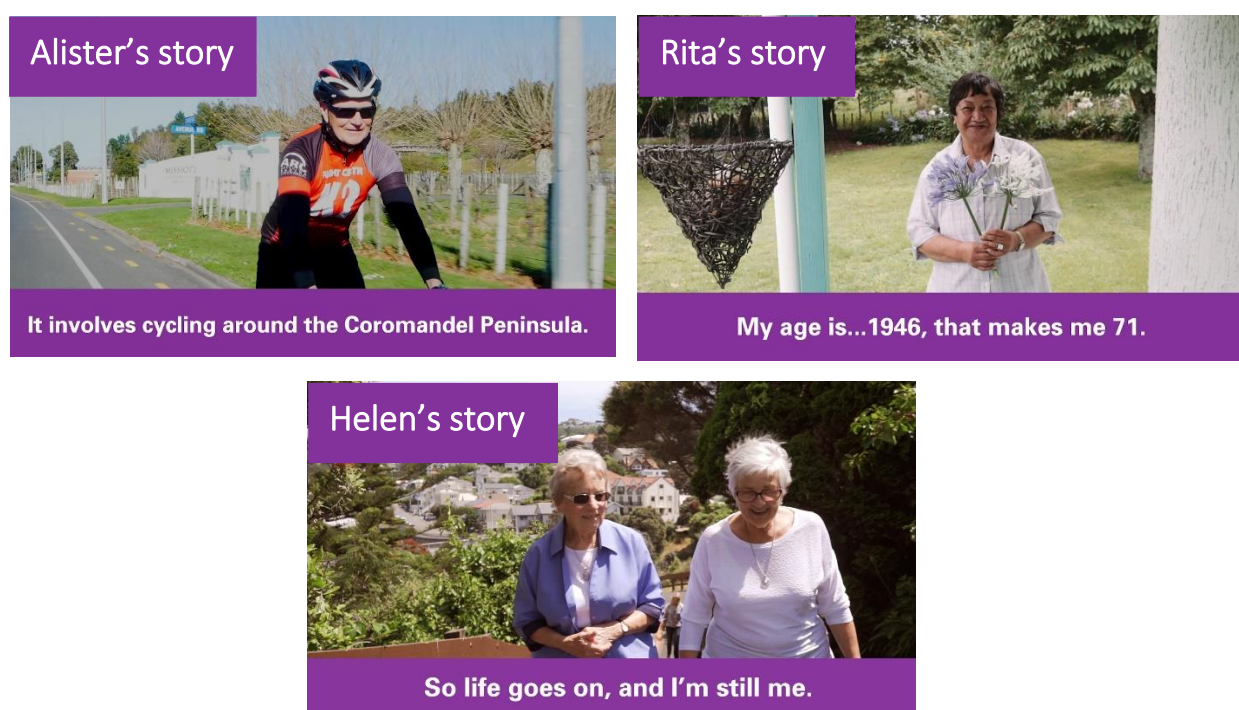


programmes and services to be accessible and inclusive of people with dementia.

Effectively the sum of the two approaches is greater than its parts. By integrating age-friendly and dementia-friendly approaches, the community is improved for the whole population.

## Meet some Kiwis who live with dementia

Hear from [Alister, Rita and Helen](#), who each have dementia. They talk about some of the things they do to help them live well with dementia in their communities.



## What is dementia?

Dementia is an umbrella term used to describe a group of symptoms that affect how well our brains work. Dementia can affect anyone, and as people get older the chances of developing dementia increase.

Each person's experience of dementia and how quickly they are affected is unique to them. The symptoms each person experiences depend on the parts of the brain that are affected. Most commonly, 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 daily lives.

Dementia is progressive, which means that for most people the changes gradually spread through the brain and lead to the symptoms getting worse. People with dementia need support from their communities to live well in their own homes and to continue doing the things they enjoy. Keeping up their usual hobbies and activities and staying physically and mentally active and socially involved are all key to maintaining abilities and wellbeing for all people, including those living with dementia. Communities that take account of the specific needs and perspectives of people living with dementia as well as those of their ageing populations will better serve their populations overall.

Dementia has considerable implications for a person's daily life and engagement and is a big concern for growing numbers people.

Learn more about dementia [here](#).

### Living well with dementia

Being diagnosed with dementia can come as a shock. However, there is a lot people can do to ensure they remain as independent as possible and continue to enjoy life for a long time to come.

Every person and every whānau/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 others sharing the same experience can help.

People with dementia are encouraged to keep involved and active in the things they enjoy. A community that supports them to do so is a dementia-friendly community.

Learn more about living well with dementia [here](#).



## The benefits of dementia-friendly communities

The benefits of dementia-friendly communities are wider than the needs of people living with dementia.



- High levels of public awareness, through increased knowledge and understanding, help to overcome stigma and misunderstanding about dementia and build a kinder, more inclusive and supportive community for people living with dementia, which is the kind of community we all want to live in.
- Clear, simple, standardised signage supports all of us, and it especially helps visitors, people who speak other languages, people who have low vision and people who process information differently.
- Improved access supports all of us, especially people with young children and people with mobility impairment.
- Improved access to leisure, recreation and social programmes benefits the total population.
- Well-designed parks and public spaces increase participation across all ages in community activities and events.
- Being enabled to lead healthier lifestyles is beneficial to people living with dementia and the wider population. Healthier lifestyles potentially reduce the risk of developing dementia and help maintain good brain and body health. Initiatives that support looking after your heart, being physically active, following a healthy diet, challenging your brain and enjoying social activities are all beneficial for everyone.

- People confident to seek early diagnosis are able to learn about and understand what is going on sooner, seek earlier intervention if relevant, access the right care and support for their situation, and plan ahead. This means it is more likely they can continue to live in their own homes.
- Educated front line response services are more likely to provide appropriate and supportive responses for people living with dementia, and again, this will benefit all community members.

Examples of community features that are *not* dementia friendly include:

- **Planning** – not including people living with dementia in the design, provision and ongoing development of plans and services.
- **Engagement in civic and community activities** – barriers exist for people with dementia to actively participate; activities are provided for people with dementia rather than planned with them.
- **Design** – facilities and environments are designed without integrating dementia-friendly design principles (see the section on ‘Dementia-friendly design’ below).
- **Buildings** – complicated, cluttered designs, internal layouts and routes.
- **Floors** – poorly maintained, rough, patterned, slippery and reflective surfaces.
- **Portals** – unclear entries and exits, unrecognisable doors, no or confusing signage.
- **Steps** – no handrail, no visual contrast, uneven steps, no ramp access.
- **Toilets** – unclear entries and exits; unrecognisable toilet, flush mechanism, hand wash and driers; non-contrasting doors, walls and floors (ie, hard to tell a door from a wall if walls, door and floor are all white); no or confusing signage.
- **Reception or service desk** – unclear where this is, unclear who is staff here, no or confusing signage.
- **Communication** – staff don’t know how to communicate effectively with someone with dementia.
- **Environments** – noisy, visually busy, cluttered, busy environments (eg, brightly patterned furnishings, abstract furniture, glaring lighting and/or deep shadowing, high thoroughfare).
- **Waiting areas** – no waiting areas, no quiet areas, no comfortable seating.
- **Thoroughfares, footpaths and accessways** – uneven or slippery surfaces, drainage problems, unclear marking, lack of clear delineation, no



separation of non-pedestrian traffic (eg, bicycles, scooters, no provision for easy access road/footpath junctures).

- **Signage** – excessive, confusing or unclear, complex language.
- **Landmarks** – loss of landmarks due to new development (eg, new road layouts, removal of landscape features such as trees, features or buildings).
- **Routines** – change or loss of routines due to new development (eg, new bus schedule, no taxi stands).
- **Transport** – not allowing passengers time to get seated before moving off, not offering to help people, rushing or ignoring people who are uncertain or confused, cold exposed bus or train shelters.
- **Policies and events** – formats that don't provide enough clarity or support for participation of people living with dementia (eg, surveys).



## Where to start

Knowing where to start can be daunting. It is easy to see that taking a dementia-friendly approach and addressing the items listed above through that lens will help improve the community for all users. One simple place to start is by reviewing the items listed above and taking a dementia-friendly approach. This would look like:

- **Planning** – co-design with people living with dementia and carers. People living with dementia are included.
- **Engagement in civic and community activities** – barriers for people with dementia are identified and addressed/reduced through a co-design



process that includes the perspectives and views of people living with dementia.

- **Design** – facilities and environments are designed with dementia-friendly design principles integrated.
- **Buildings** – simple, recognisable, clear designs, layouts and routes.
- **Floors** – well-maintained, even, plain, non-slip and non-reflective surfaces.
- **Portals** – clear signage, entries and exits; recognisable contrasting-colour doors.
- **Steps** – handrails, clear contrast, even steps, ramp access.
- **Toilets** – clear signage, entries and exits; recognisable toilet, flush mechanism, hand wash and driers; contrasting doors, walls and floors.
- **Reception or service desk** – clear signage, easy to locate and identify, clear who is staff here (uniform, name tag).
- **Communication** – education is provided to staff to increase their communication skills and understanding of dementia. Patient, respectful, empathic, responsive and skilled customer service is provided.
- **Environments** – calm, quiet, uncluttered environments (eg, plain furnishings, recognisable furniture, gentle lighting with no deep shadowing, managed clear thoroughfare).
- **Waiting areas** – waiting areas are provided, including quiet areas and comfortable seating.
- **Thoroughfares, footpaths and accessways** – even, well-maintained non-slip surfaces, effective drainage, clear marking, clear delineation, separation of non-pedestrian traffic (eg, bicycles, scooters, provision for easy access road/footpath junctures).
- **Signage** – essential, clear, easy to see and read, plain language, include recognisable visual prompts where possible.
- **Landmarks** – consideration paid to landmarks (value as wayfinders, retention and impact of loss).
- **Routines** – consideration paid to routine changes, testing of impact, management of communication of change.
- **Transport** – waiting for passengers to get seated before moving off, offering to help people, taking time to help people who are uncertain or confused, well-designed weather-proof bus or train shelters, educated and aware staff, clear signage.
- **Policies and events** – clear supported formats that enable participation of people living with dementia.

Taking a step-by-step approach is helpful. There are a lot of simple, easy changes that can be made. The list above offers suggestions of where to focus effort, but each element is not mandatory. Some steps may be relevant to your community and to the environment you are working on, and others may not be relevant or may be beyond your control or budget. We recommend starting with what you can change and influence and working from there.



### Including the voice of people living with dementia – co-design

The Alzheimers NZ [Dementia Declaration](#) states: “Our lives matter. As New Zealanders living with dementia, we are citizens whose lives matter. We have the same rights, privileges and obligations as everyone else. We live our best possible lives when... we live in knowledgeable communities that include, accept and understand us.”

A core fundamental of a dementia-friendly approach is the involvement of people living with dementia (people with dementia and carers) in the development, design, work and evaluation of the programme. “[Nothing about us without all of us](#)” is a statement from [Dementia Alliance International](#) (representing people with dementia across the world) which is designed to clearly communicate that it is essential that work for people with dementia be informed by and have input from people living with dementia. People with lived experience are central to planning. This can be achieved through co-design work.

### Get the right stakeholders involved from the start

A community project needs strong leadership, budget and support from councils, stakeholders and interested parties. In addition to key age-friendly stakeholders, a dementia-friendly approach means including as stakeholders:

- people living with dementia and carers
- the local Alzheimer's or dementia organisation (find your local expert organisation [here](#))
- local care, social and health sector representatives
- local hapū and iwi.

## Literature review

Across the world more and more communities are working to become dementia friendly. Conducting a literature review to identify current relevant examples of others' work, strategies and actions will help refine and inform plans. It is also important to recognise the unique aspects of Aotearoa New Zealand that inform our own cultural identities – that is, some examples from overseas may not translate or fit with a New Zealand approach. Links to examples from New Zealand and overseas are provided below.

## Raising awareness and increasing understanding – education

Working to raise awareness and understanding of dementia to build a more inclusive, accepting and respectful society and challenge stigma, fear and misunderstanding is an important part of dementia-friendly work and different from age-friendly work. Education that raises awareness and tackles stigma and misunderstanding is a key element of being dementia friendly.

A great place to start is Alzheimers New Zealand's online [Dementia Friends](#) programme. It only takes about 20 minutes. Dementia Friends is an awareness programme and social movement designed to help people start to learn about dementia and to understand how they can help. The programme provides a good baseline of awareness upon which organisations can then build dementia-specific education that relates to its role and relationship with its customers.



In each region throughout New Zealand there is a local Alzheimer's or dementia organisation. These are the expert providers of support and services, including education. You can work with your local organisation to develop education that meets the needs of your organisation, its customers and staff.



## Understand your population

Use census and other population data available and talk to your local Alzheimer's or dementia organisation experts to understand the population and demographics of people living with dementia in your community. You can then use this information to further inform your workplan.

## Take the right aim

Include developing dementia-friendly specific aims in your age-friendly work so that these are clearly identified within the overall work programme. Your dementia-friendly aims should be informed by your stakeholders and relevant for your community. Possible examples of dementia-friendly aims and considerations include:

- **Education** – increase community awareness and understanding of dementia by providing awareness education to the community.
- **Social** – Help people remain independent and participating in the community for as long as possible. Strengthen community supports to increase inclusion. Create opportunities for people living with dementia to be involved and participate in their community (eg, through clubs, groups, activities and volunteering).
- **Businesses and organisations** – encourage businesses and organisations to become dementia-friendly through staff education. Councils can lead the way by their leadership teams and all staff completing awareness-raising education.
  - [Dementia Friends](#) is a short online 20-minute awareness-raising education module that anyone can do. Dementia Friends is also available as a 1-hour face-to-face session – contact [dementiafriendlynz@alzheimers.org.nz](mailto:dementiafriendlynz@alzheimers.org.nz) for details.
  - Businesses and organisations can then identify and roll out additional dementia education their staff may need related to the customers and services they provide.
  - Businesses and organisations can becoming recognised as dementia friendly by enrolling in Alzheimers New Zealand's [Dementia Friendly Recognition Programme](#). The programme focuses on learning from people with dementia; dementia-friendly environments, customer service, communication and publication; and flexible working for staff. Councils can lead the way by enrolling public-facing services such as customer centres,

libraries, museums and other public-facing services. Dementia-friendly community programmes can include targeted efforts to enrol local businesses and organisations in the cause by becoming dementia friendly.

- **Environment** – Assess and improve the community’s physical environments to be more dementia friendly. Remove barriers and improve design in the built as well as social environment. Councils can again lead the way by reviewing their environments and developing plans to change and improve. Relevant examples are available through searching the Internet.
- **Political** – It is important to provide adequate levels of home support, affordable and appropriate housing, respite care and residential care when community living is no longer desirable or possible. Initiate a broader discussion with central government about the needs of local populations with the aim of gaining political commitment and resources.

These can then be broken down into objectives and step-by-step actions to achieve your aims.



### Dementia-friendly design

Application of universal design principles in the consideration and development of built and created environments is a good start. Dementia-friendly design incorporates a wider remit of actions than age-friendly design.

There is a wide range of dementia-friendly design information readily available on the Internet, and specific subjects such as toilets and environments are

available. To begin with, you can start learning from the experts at the [Dementia Services Development Centre \(DSDC\)](#) at the University of Stirling.

A range of dementia-friendly design guidelines are also available at the following two links:

- [Dementia Australia – Building & garden design](#)
- [Dementia Australia – Environmental Design Resources](#)

## **Dementia-friendly communities – examples**

Dementia-friendly community initiatives are growing across the world. Some examples are provided below. This is not an exclusive list.

### **Rotorua**

- [Dementia-Friendly Rotorua](#)

### **Christchurch**

- [Developing a Dementia-Friendly Christchurch](#)

### **Australia**

- [Creating Dementia-Friendly Communities: A Toolkit for Local Government](#)
- [Living Well, Longer](#)
- [Dementia project run by Alzheimer’s WA helps one country town learn to carry on with life](#)

### **Scotland**

- [Dementia ... Everyone’s Business](#)

### **UK**

- [DEEP Guides](#)
- [What is a dementia-friendly community?](#)
- [Creating a dementia-friendly York](#)
- [A Dementia Friendly City: A strategy and action plan for dementia services within the City of London 2013–2015](#)

### **USA**

- [Minnesotans working together on the impacts of Alzheimer’s](#)
- [Dementia-Friendly Community Action Plan 2016](#)





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