



dementia
friendly
communities

Creating Dementia-friendly Communities Community Toolkit



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The Dementia Australia Dementia-friendly Toolkit was first created in 2014, utilising a range of international resources on dementia-friendly communities and age-friendly communities. This toolkit has been updated and reflects the 2018 Dementia-friendly Communities program.

Dementia Australia would like to acknowledge Innovations in Dementia for informing the original development of this resource (innovationsindementia.org.uk/).

Dementia Australia would also like to acknowledge and thank the Dementia-friendly Communities Dementia Advisory Group, for its ongoing guidance and commitment to being dementia-friendly.

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Introduction

This toolkit contains information and the process required to become recognised by Dementia Australia as a dementia-friendly community.

The purpose of this toolkit is to provide community groups with the knowledge and tools required to understand dementia, and to be recognised by Dementia Australia as a Dementia-Friendly Community.

What is dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

They are all diseases of the brain which may result in practical difficulties with:

- remembering things
- completing everyday tasks, such as handling money
- communication, such as language or word finding
- perception

Dementia is a progressive disease with mild symptoms in the early stages of the disease which generally worsen over time. Dementia affects everyone differently, and in fact, not everyone you meet living with dementia may have any visible symptoms. Dementia can happen to anybody, but it is more common after the age of 65.

In 2018, dementia affects an estimated 436,000 Australians, with this number set to rise to almost 1.1 million by 2058.

The majority of people living with dementia live in the community. Often people feel socially isolated and wish they had more opportunities to interact with people and to participate in social or other activities. With the support of their employer, local businesses, organisations, neighbours, friends and family, people living with dementia can continue to do many of the things they did before they received a diagnosis.

What do people living with dementia say?

Dementia Australia conducted its first national survey of people living with dementia in 2014 to identify priorities for tackling the stigma and social isolation associated with dementia in the community. Further to this, a key finding from the Dementia Australia (August 2017) *Dementia and the impact of stigma report*, found people living with dementia and care partners are significantly more lonely than other members of the general public.

People living with dementia indicated the need for changes to our communities to make our communities more dementia-friendly, and to support people living with dementia to continue to live well and to be involved in the activities they enjoyed before a diagnosis.

People living with dementia identified the following priority areas for communities to become dementia-friendly:

1. Increasing community awareness and understanding about dementia.
2. Improving access to social activities and opportunities for engagement including volunteering.
3. Employment opportunities or support to remain employed.
4. Access to appropriate health and care services to support people living with dementia to continue living at home for as long as possible.
5. Access to affordable and convenient transportation options.
6. Improving physical environments including appropriate signage, lighting and colours.

What is a dementia-friendly community?

A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value. Each dementia-friendly community will look different, but may include:

- Businesses that provide accessible services to people living with dementia including trained staff who understand dementia and know how to communicate effectively with people who have dementia.
- Employers that provide support for people living with the disabilities of dementia to continue with paid employment.
- Volunteering and paid employment opportunities for people living with dementia.
- Memory cafes for people living with dementia and their families. These are generally informal and social gatherings where people feel welcomed and accepted, remain socially active, and make new friends.
- Choirs, walking groups, sporting clubs and social groups that welcome members living with dementia.
- Adult education facilities that provide opportunities to support new learning, for example courses at tertiary institutions, TAFE, or learning a new language or instrument.

What is a dementia-friendly organisation?

Dementia-friendly organisations are businesses or other organisations (including local government and community services) that want to make changes to their operations, procedures and environment to better meet the needs of people with living dementia.

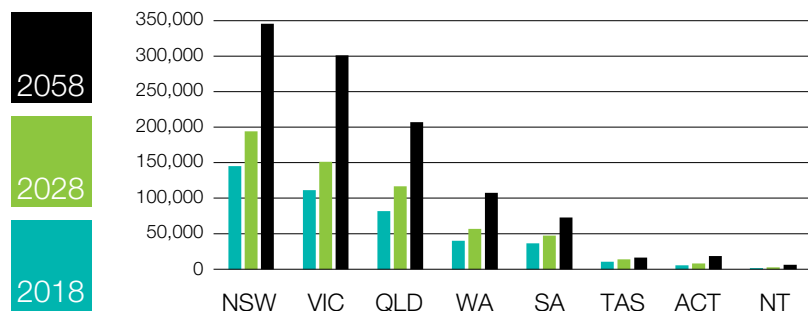
Becoming a dementia-friendly organisation requires training, education and looking at the world of people living with dementia through a different lens.

Each dementia-friendly organisation will look different, but may include:

- Accessible services and training for employees to understand dementia.
- The provision of support for people living with dementia, enabling continued paid employment.
- Volunteering opportunities.
- Transportation options that are reliable and staffed with people who understand the cognitive deficits associated with dementia.

Why do we need to be dementia-friendly?

The growing numbers of people living with dementia requires a shift in how we respond to the needs of people living with dementia in the community. As the population ages, we will see an increase in the number of people living with dementia.



Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra. These data exclude Gerard Community Council, Maralinga Tjarutja Community Inc, Nepaburna Community Council, Outback Communities Authority and Yalata Community because of very small numbers, Belyuen Community Government Council because of very small numbers and the unique territories of Christmas Island and Cocos Islands, and Cue, Murchison, Sandstone and Upper Gascoyne Local Government Areas because of very small numbers.

How do we become a dementia-friendly community?

First, become a Dementia Friend

Start by becoming a Dementia Friend and increasing your personal awareness of dementia and its impacts. A little understanding and kindness can go a long way.

Sign up and become a Dementia Friend via dementiafriendly.org.au

Then, become a Dementia-friendly community, recognised by Dementia Australia

Communities independently develop their own dementia-friendly action plan using this toolkit, templates and resources available on the Dementia-Friendly Communities website.

No two dementia-friendly communities are alike, however they often represent a town or regional area. A dementia-friendly community must include a group of people living with dementia alongside others such as carers to act in an advisory capacity (often referred to as a dementia alliance) and a designated contact person.

1. Get people on-board and **form a local Dementia Alliance**
2. **Complete an action plan** (see page 12) and submit to the dementia-friendly communities team at Dementia Australia.
3. **Promote** what you are doing
4. Stay involved, review and **get others involved!**

If you have any questions please contact the team via email dementiafriendly@dementia.org.au or phone 02 6278 8900.

Alternatively, you can pay for support, consultation and practical assistance from the Centre for Dementia Learning consulting services to help develop an action plan. Find out more about using Dementia Australia's Centre for Dementia Learning consulting services via dementialearning.org.au/consultancy, phone 1300 DEMENTIA | 1300 336 368 or email CDL@dementia.org.au



Dementia-friendly recognition

As a “Dementia Australia Recognised Dementia-friendly Community” you will receive a Dementia-Friendly Communities marketing pack, and you will be linked with our website, via our communities in action (showcasing stories of dementia-friendly activity from around Australia) and community map (online map displaying location of dementia-friendly activity and organisations).

The Dementia-Friendly Communities marketing pack includes:

- A letter of thanks and congratulations from Dementia Australia CEO Maree McCabe
- A certificate recognising your organisation's efforts towards becoming dementia-friendly
- Dementia-friendly symbol/logo and guidelines
- Dementia language guidelines
- Dementia-friendly key messages
- Resources and help sheets.

To discuss further please contact the dementia-friendly team via email dementiafriendly@dementia.org.au or phone 02 6278 8900. We can also help determine which pathway may work best for you.

The Dementia-friendly Recognition Symbol

Background

The dementia-friendly symbol was developed in consultation with people living with dementia as part of the 2014 Dementia Australia (previously Alzheimers Australia) Dementia-Friendly Communities pilot program.

The symbol signifies an organisation, business or community that has been recognised by Dementia Australia as working towards being dementia-friendly.



Guidelines for use

Organisations recognised by Dementia Australia as working towards becoming dementia-friendly can use the symbol. These organisations are making a commitment to be more aware of the needs of people living with dementia and strive to provide an improved service. It is an ongoing commitment to better meet the needs of the organisation's customers or clients who are living with dementia. For people living with dementia, seeing the dementia-friendly symbol displayed, will mean that an organisation has staff who are specially trained and have an understanding of dementia.

Displaying the symbol signifies that a community has developed their own dementia-friendly action plan. This action plan addresses the essential principles outlined in this toolkit for dementia-friendly communities.

- The dementia-friendly symbol and digital logo are included as part of the dementia-friendly communities marketing pack, along with a letter of congratulations and a certificate recognising dementia-friendly status.
- Displaying the dementia-friendly symbol signifies organisations and businesses are recognised by Dementia Australia as being Dementia-Friendly.
- Displaying this symbol signifies that organisations have a dementia-friendly action plan in place.
- The symbol can be displayed at your place of business including shopfront, and used in electronic correspondence.
- The symbol may be used electronically on organisational letterhead, email signature blocks or for promotion.
- The electronic symbol should not be modified or re-sized in any way, and if included should be used only in the year it is current.
- Dementia Australia reserves the right to revoke permission to use the dementia-friendly symbol at any time.

For more information about the dementia-friendly symbol please contact the dementia-friendly team via dementiafriendly@dementia.org.au or 02 6278 8900.

Benefits

Why becoming dementia-friendly will help my community

The increasing number of people living with dementia across Australia deserves the highest quality of service and care from organisations.

Becoming a recognised dementia-friendly community demonstrates your commitment to improving the lives of people living with dementia, their families and carers.

Our community is increasingly aware of dementia-friendly organisations and are choosing organisations that are committed to staff education to ensure well-being for loved ones living with dementia. The amount of training staff need will depend upon their role.

Many communities and organisations have already received recognition for becoming dementia-friendly. You will find a list of Dementia Australia recognised Dementia-Friendly Organisations available on our online community map (www.dementiafriendly.org.au/community-map).

Dementia-friendly community benefits

Many communities are taking steps to ensure they are as dementia-friendly as possible. These communities understand the impact dementia can have on a person's daily life.

A dementia-friendly community believes in accepting people living with dementia for their individuality and does not define people living with dementia by their condition.

Benefits for business

- Enables you to better meet the needs of people living with dementia, whether they are your volunteers, clients or customers.
- Being dementia-friendly means you are inclusive, people-friendly and recognise people living with dementia as equal members of the community.
- It shows you are responsive to the needs of the community. Statistics tell us 70% of people living with dementia live in our community – and many people still actively engage in community life and do shopping, banking and dine at cafes.
- Additional and complementary professional development supports better staff retention and enhanced positive culture.
- It makes the environment more suitable for people living with dementia (such as helpful signage/

lighting/atmosphere) and in turn makes the environment more suitable and accessible for a broad and aging population.

- When a community is dementia-friendly it becomes more accessible; there is a feel good factor which leads to positive customer experiences. This positive experience leads to repeat business.

Examples communities can take to become dementia-friendly:

- A bank could identify a staff member for dementia training to provide services to people living with cognitive impairment.
- A retail outlet could examine their layout and signage to ensure easy access, helpful signage and lighting for people living with a cognitive impairment.
- A community group could support a volunteer program that includes people living with dementia.

Benefits for individuals (staff, volunteers)

A basic understanding of the impact of dementia and how to support and communicate with people living with dementia can make a significant difference to the experience of paid staff, volunteers and general members of a community.

Benefits may include:

- Expanded knowledge of dementia.
- Improved customer service skills, responsiveness and sensitivity to community needs.
- Increased individual happiness as a result of helping and making a difference to others, while becoming part of a movement to improve the world for people living with dementia.

Benefits for people living with dementia

People living with dementia may need extra support or understanding when they interact within the community. The experience of the person living with dementia in a public situation will vary but may include:

- Problems remembering what they are doing, disorientation and confusion, especially in complex or confusing environments. Difficulties with communication – language and word finding impairments.
- Problems handling money.
- The person living with dementia may appear to have no symptoms at all.

How the community responds to people experiencing these issues can make a real difference for the person living with dementia.

When actively engaged and included (for example by dementia-friendly organisations) people living with dementia will feel more inclined to ask for help, when and if needed. This enables the person living with dementia to:

- Maintain independence for longer.
- Continue engaging in community life, such as shopping, dining at cafes and restaurants, and visiting local businesses.
- Stay at home longer and delay entering residential aged care.
- Participate in society and keep their mind active; e.g. using ATMs
- Maintain executive functioning (skills used for planning and doing tasks, regulating behaviour, impulse control, and attention).
- Enjoy a more fulfilling and socially active lifestyle.

Additional information available

Dementia-friendly business guide: Toolkit on working towards becoming a dementia-friendly organisation (Alzheimer's Society 2017)

actonalz.org/sites/default/files/documents/dementia-friendly_business_guide.pdf

Start a dementia alliance

Do you want to make your local community more dementia-friendly? You can start today by setting up a local dementia alliance or group in your community.

What is a dementia alliance?

A dementia alliance is made up of people living in the community who are interested in helping to make their community or town more dementia-friendly.

A dementia alliance must include:

- people living with dementia, alongside care partners and family members of people living with dementia
- a designated contact person.

A dementia alliance could include:

- business owners, managers or staff
- community group members
- service providers
- members of the local council or government agency
- anyone who is interested

A dementia alliance or group will look different in every community and will depend largely on who is involved and the aims of the group.

Steps could include:

1. Find people who may be interested in starting a group with you.

Encourage these individuals and community members to find out more and become a Dementia Friend (dementiafriendly.org.au)

2. Organise a meeting.

Catch up over coffee!

3. Make your first meeting a success.

To do this you could:

- Discuss group aims. Why are you all coming together?
- Chat about possible activities and what you would like to achieve. This could include:
 - Local businesses providing accessible services to people living with dementia.
 - Helping staff understand dementia and how to communicate effectively with people living with dementia.
 - Employers supporting people with younger onset dementia to remain employed, in the same way people living with other disabilities can remain employed.
 - Improving signage.
 - Choirs, walking groups, sporting clubs and social groups that are welcoming and inclusive for people living with dementia.

- Who is responsible for what? And who else could be part of the group?

- Think about timelines...

4. Take action!

- Schedule regular meetings, and create a dementia-friendly community action plan (see dementiafriendly.org.au/resources)
- Spread the word and promote your alliance. Encourage as many people as possible to join you.
- Let Dementia Australia know what you are doing. Request to be included on the dementia-friendly community map.

Creating Dementia-friendly Communities Templates



Dementia-friendly community action plan template

This dementia-friendly community action plan will help you to set out what your dementia alliance group would like to achieve, and help track your progress as you go.

When you are happy with your plan

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The community action plan template can be completed online at dementiafriendly.org.au/become-a-dementia-friendly-community. Use the template guide below to help you prepare responses to the Essential Principles questions asked.

Group name:			
Group location:	Include postcode		
Contact	Who is your group contact or coordinator? (name, email, phone)		
Who are we?	List members and provide a short description of your group		
Our commitment to creating a dementia-friendly community	What would you like to achieve? Why is this important to your local community?		
Aim	What is the main aim of the group?		
Action	Responsibility	Timeline	Progress
List the possible actions required to achieve this aim	Who will be responsible?	When will this action be completed?	Progress to date
Aim #1: Outline aim	Possible aim: Form a local dementia alliance.		
Aim #2: Outline aim	Possible aim: Raise awareness and reduce stigma in our local community.		
Aim #3: Outline aim (add additional columns as required)	Possible aim: Apply for community grant funding to support our dementia friendly community aims.		
This plan for the community of <i>(INSERT group name)</i> was drafted on <i>(INSERT date here)</i>			
Signed by members of the local alliance group:			
Member name	Member name	Member name	Member name
Member name	Member name	Member name	Member name

Commitment statement template



Dementia-friendly Communities Statement of Commitment

The management and staff of *[Organisation / Business name]* make the commitment to work towards being a dementia-friendly organisation. In making this commitment, we acknowledge and agree that:

- We will involve people living with dementia in the process of becoming dementia-friendly
- We value people living with dementia and aim to support social inclusion in our business operations
- We will strive to create broader awareness of dementia amongst our staff
- We will support staff to receive dementia awareness training and become Dementia Friends
- We will review our current practices and make changes to be more dementia-friendly
- We will work towards implementing the dementia-friendly strategies provided by Dementia Australia
- We will also identify and develop strategies that are tailored specifically for our business that align with the dementia-friendly principles
- We will follow the guidelines for use of the dementia-friendly symbol
- This is a genuine commitment to social change and we will continue to review our activities to achieve this dementia-friendly goal.

Signature

Name and position

Date

Checklists

Creating dementia-friendly communities

It is important to consider both the physical and social environment of a community in order to identify possible areas of improvement.

There are a range of steps you and your community can take to help people living with dementia to remain engaged in the community in a meaningful way. This can be done by ensuring the physical environment is easy to navigate and safe for people living with dementia. Many of these suggestions will benefit all members of the community.

This checklist is not exhaustive – remember to speak with people living with dementia and ask what could make a difference.

Some important things to consider when designing indoor and outdoor physical environments include:

Outdoor Areas and Buildings	
Public areas and parklands are clean, well-kept and pleasant	
Outdoor seating is safe, well maintained and adequate in number	
Undercover areas in parklands are provided to ensure accessibility in all weather conditions	
Footpaths are wide, level where possible, non-slip, well maintained and free of obstructions	
Bicycle pathways are separate from footpaths and other pedestrian walkways	
Adequate number of pedestrian crossings which are functional for people with different levels of disability with non-slip markings	
Pedestrian crossings have visual and audio cues and provide sufficient crossing time	
Visual landmarks are in place to assist way-finding such as garden beds, murals, water fountains/features	
Building entrances buildings are clearly visible and obvious	
Adequate and evenly distributed street lighting to assist those with dementia and lower visual acuity	
Level changes are clearly marked and well lit with handrails and non-slip, non-glare surfaces	
Buildings are well-signed outside and inside, with sufficient seating and toilets, accessible elevators, ramps, railings and stairs, and non-slip floors	
Indoor and outdoor public toilets are well-maintained, clean, accessible and adequate in number with appropriate signage	
Bus shelters are enclosed and have adequate seating	
Street clutter including excessive signage, music, advertisements and bollards are minimal	
Background noise is minimal with acoustic barriers such as grass rather than hard surfaces, trees, hedges and fencing in place	
Signs have large graphics and symbols in clear colour contrast to the background, preferably dark lettering on a light background	
Signs have non-glare lighting and non-reflective coverings	
Quiet space available for someone who might be anxious or confused	

Indoor Areas

Steps clearly marked and lit, with guard and handrails on both sides, smooth, nonslip, non-glare surfaces, and nearby seating	
Doors with lever-type handles and no more than 2 kilograms of pressure to open	
Uninterrupted visual access to all areas, ideally with unobstructed view of at least 6 to 30 metres in both directions in buildings and other indoor areas	
Simple signage giving clear and essential information only	
Signage fixed to walls at eye level (around 1400–1700mm above floor level where possible)	
Well-maintained, plain, smooth, level, non-slip, non-reflective floor coverings	
Flooring in clear colour contrast and material to walls and furnishings	
Changes in texture or colour of floor coverings to indicate potential hazards	
Colour contrast toilet seats with toilet bowls and floor and uniform signage for male and female toilets	
Sound absorbing materials, for example, acoustic ceiling tiles, wall hangings, upholstery and curtain fabrics used where possible	
Indirect lighting for a good illumination level with reduced glare	
No areas of deep shadow or glaring light.	
Alarms/sirens/auditory cues on low frequency and at suitable pitch for people with low hearing acuity	
Corridors at least 2 metres wide to enable those less ambulant and wheelchair users to safely pass oncoming people	
Where complete visual access is not possible, distinctive way-finding cues positioned at point where visual access ends. For example, potted plants, ornaments, paintings	
Furniture and furnishings should be contrasted against walls for easy visibility. Furniture should have rounded edges to reduce bumps and grazes	
Simple layout with non-uniform, short, direct routes	
Where possible, a minimum of corridors no longer than 22 metres in length with no blind bends	
Quiet space available for someone who might be anxious or confused	

Opportunities for social engagement are integral to ensure the person with dementia remains actively involved in their community. There are a range of activities that communities, neighbourhoods and family and friends can employ to ensure people with dementia can contribute and participate in everyday activities in a meaningful way.

Social Engagement	
A range of community events and activities are available to meet the diverse population of people with dementia including dementia-specific activities as well as mainstream activities that are supportive of people with dementia	
People with dementia are included in community initiatives and projects to provide their input and feedback	
People with dementia are supported to speak at conferences and local events about dementia	
Community events and activities are held at convenient times during the day for people with dementia	
Community events and activities are held that can be attended either alone or with a carer	
Affordable transportation options are available to people with dementia	
Information about community events and activities are readily provided including details regarding accessibility of facilities and transportation options	
Venues for community events and activities are conveniently located, accessible, well-lit and easily reached by public transport	
Outreach to include people at an increased risk of social isolation including CALD, A&TSI, LGBTI, living alone and homeless to remain engaged in their community	
People with dementia are recognised for their past and ongoing contributions to their community	
Dementia awareness activities and events are held to increase community knowledge and understanding of dementia	
Local support groups for people with dementia, their carers and family members are available e.g. Memory Cafés	
People with dementia are regularly consulted by public, volunteer and commercial services on how best to serve them	
Hobby and interest groups provide support to assist people with dementia to remain engaged e.g. choir, walking groups	
Sporting clubs and community organisations are aware of the needs of people with dementia and ensure that services are tailored to support people with dementia as needed	
Local government, community organisations and businesses provide staff training on how to effectively communicate with customers with dementia	

Social engagement goes beyond participation in community events. For some people this could include employment, volunteering and studying. An opportunity for people with dementia to remain involved in such activities as they did pre-diagnosis is important to ensure meaningfulness and quality of life.

Employment, Volunteering and Study	
Disability support services to engage with people with dementia	
Flexible and appropriately paid opportunities for people with dementia to continue working, or become employed are promoted	
Decision-making bodies in public, private and voluntary sectors encourage and facilitate membership of people with dementia	
Employment programs to support people with dementia undertake a range of activities are provided and promoted	
Workplaces are adapted to meet the physical needs of people with dementia	
Training and education opportunities for people with dementia are provided and promoted	
Qualities of people with dementia who are employed are well promoted and recognised	
Volunteering opportunities are offered and promoted by communities, businesses and organisations to promote social engagement	
Training and education opportunities for people with dementia are provided and promoted	
Adequate support is provided by training and education institutions to people with dementia undertaking further study	
People with dementia are consulted in order to ascertain who they can best be supported in the workplace and education and training institutions	
Flexible options for people with dementia to volunteer are available with training, recognition, guidance and compensation for personal costs	

This checklist was adapted from Innovations in Dementia, Checklists for dementia-friendly environments 2012 and the World Health Organisation Checklist of Essential Features of Age-friendly Cities 2007.

This checklist was updated in 2018, and reflects feedback from the national DFC Dementia Advisory Group.

Communication and social media templates

How to use these templates

This resource contains suggested internal and external communication templates to support your dementia-friendly activity. You could use this as a starting point when customising your message/s. It includes:

Internal communications

1. Suggested email to encourage sign-up to the Dementia Friends program
2. Suggested follow-up email to sign-up to the Dementia Friends program
3. Suggested email to promote community events that are dementia-friendly.

External communications

1. Suggested newsletter copy
2. Suggested social media posts

Additional content and resources are available on the dementia friendly communities website www.dementiafriendly.org.au

For dementia key facts and statistics, please visit dementia.org.au/statistics.

Please stay connected and send your stories (with photo/s) to dementiafriendly@dementia.org.au, we will include in our communities in action web page as appropriate.

Internal communications

1. Suggested email to promote Dementia Friends

Subject: Show your support for people living with dementia

Dear <name>,

<Insert dementia alliance group name> is proudly supporting Dementia Australia's Dementia Friends program.

With an estimated 436,000 Australians living with dementia and 250 Australians joining the population living with dementia each day, it is critical we increase our understanding of the condition.

For this reason, Dementia Australia is asking individuals, communities and organisations to become Dementia Friends and learn how small actions can make a big difference in the day-to-day lives of people living with dementia, their families and carers.

As part of our role as a dementia alliance group we are supporting the program and encouraging you to sign up to become a Dementia Friend.

Simply visit www.dementiafriendly.org.au and complete a short online module that contains explanations and interviews with people sharing how dementia has impacted their lives and what others can do to support them in day-to-day situations.

It's a great way to find out how, with increased knowledge and understanding, you can better support someone impacted by dementia.

Upon completion of the module, you will receive a Dementia Friend certificate and you may also order a badge.

Head to www.dementiafriendly.org.au and start making a difference today.

[insert sign-off]

With increased awareness and understanding, we can help transform the way we, as a community, think, act and talk about dementia.

2. Suggested follow-up email

Subject: Reminder to show your support for people living with dementia

Dear <name>,

As supporters of Dementia Australia's Dementia Friends program, we recently encouraged you to sign up to become a Dementia Friend, and through increased awareness and understanding, make a positive difference to the lives of people living with dementia, their families and carers.

It's been great to hear how so many of you have become Dementia Friends and are supporting such an important initiative.

If you've not yet had the chance, we'd like to remind and encourage you to visit www.dementiafriendly.org.au and learn about the small, everyday things that we can do to help people living with dementia to remain included, accepted and connected within their community.

With compassion and understanding, you can make a positive difference to the lives of people living with dementia, their families and carers.

Join us and thousands of others who have already signed up to become a Dementia Friend. Head to www.dementiafriendly.org.au and start making a difference today.

Thank you.

3. Suggested email to promote community events

Subject: Show your support for people living with dementia on <name of campaign>

Dear <name>,

In support of Dementia Australia we are encouraging the community to become Dementia Friends and make a positive difference to the lives of people living with dementia, their families and carers.

Becoming a Dementia Friend is a simple yet effective way to show our support.

If you haven't already signed up to this program, it is as easy as visiting dementiafriendly.org.au and completing a short module that explains dementia and some of its impacts.

By becoming a Dementia Friend, and increasing your awareness of dementia and its impacts, you can help a family member, friend, neighbour or co-worker living with dementia feel accepted, included and involved.

A little understanding and kindness can go a long way.

Thank you.

External communications

1. Suggested newsletter copy

Dementia-friendly Communities are places where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

The small actions that people take every day can make a big difference for people living with dementia, their families and carers. Dementia Australia is asking individuals to become a Dementia Friend, and through increased awareness and support, make a positive difference to the lives of people living with dementia.

The Dementia Friends program aims to transform the way we, as a community, think, act and talk about dementia.

Currently, an estimated 436,000 Australians are living with dementia and 250 people are joining the population living with dementia each day¹. It is the second leading cause of death of Australians and the leading cause of death among Australian females².

Dementia Australia's Dementia Friends program is an informative online resource for people interested in learning about dementia and wanting to be empowered to do small, everyday things that can make a big difference to a person living with dementia.

To become a Dementia Friend, visit dementiafriendly.org.au and watch three short videos that explain dementia and feature interviews with people impacted by dementia.

Becoming a Dementia Friend makes you aware of the small, everyday things you can do to support people living with dementia to remain included, accepted and connected within their own community. With compassion and understanding, you can make a positive difference to the life of someone living with dementia.

Anyone can become a Dementia Friend. Already thousands of people, including politicians, businesses, communities and individuals have signed up and pledged their support for people living with dementia.

It starts with you. Head to dementiafriendly.org.au and start making a difference today.

¹ The National Centre for Social and Economic Modelling NATSEM (2016) *Economic Cost of Dementia in Australia 2016–2056*

² Australian Bureau of Statistics (2017) *Causes of Death, Australia, 2016* (cat. No. 3303.0)

2. Suggested/example social media posts

Twitter

Your small actions can make a big difference. Join us in supporting @DementiaAus, become a Dementia Friend and help transform the way we, as a community, think, act and talk about #dementia. Visit dementia.org.au #dementia2018

Facebook

Your small actions can make a big difference. Join us in supporting @DementiaAustralia, become a Dementia Friend and help transform the way we, as a community, think, act and talk about #dementia. Become a Dementia Friend at dementiafriendly.org.au today. #dementia2018

Instagram

Small actions Big difference. Join us in supporting @dementia_australia, become a Dementia Friend, and help transform the way we, as a community, think, act and talk about dementia. Become a Dementia Friend at dementiafriendly.org.au today. #dementia2018



Creating Dementia-friendly Communities Resources



Dementia language guidelines

The words used to talk about dementia can have a significant impact on how people view or treat people living with dementia in our community. Respectful language is important and recognises that dementia is not the defining aspect of someone's life and does not prejudge their capacity or level of understanding.

Dementia Australia developed *Dementia language guidelines* alongside people living with dementia. The purpose of the guide is to promote the consistent use of appropriate inclusive and non-stigmatising language when talking about dementia.

These guidelines are designed to promote the consistent use of appropriate, inclusive and non-stigmatising language when talking about dementia and people living with dementia.

They are useful when working with media organisations or promoting the wonderful work you are doing. Please become familiar with this resource and feel free to download and share widely.

Please visit dementiafriendly.org.au/resources/dementia-language-guidelines

Dementia Language Guidelines

The purpose of this paper is to promote the consistent use of appropriate, inclusive and non stigmatising language when talking or writing about dementia and people living with dementia.

What is appropriate language for talking about dementia and why do we need it?

The words used to talk or write about dementia can have a significant impact on how people living with dementia are viewed and treated in our community.

The words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression. A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person with dementia experiencing stigma or discrimination.

Appropriate language must be:

- Accurate
- Respectful
- Inclusive
- Empowering
- Non-stigmatising

Everyone deserves respect

Respectful language recognises that dementia is not the defining aspect in the life of someone with a diagnosis and does not reflect their capacity or level of understanding. It is important to respect others preferences about words used about them, regardless of whether the person being talked about is present or not.

Be mindful of not reinforcing stereotypes or myths about dementia.

It is important to know the facts about dementia. For example, dementia is not a normal part of ageing, nor is memory loss the only symptom. Dementia can affect language, planning, problem solving, behaviour, mood and sensory perception.

Talking about dementia in a negative manner or by using incorrect terminology or inaccurate facts can reinforce stereotypes and further exacerbate the myths and misinformation about dementia.

Everyone's experience of living with dementia is unique, as there are many different types of dementia and symptoms may present differently in different people. You can find more information about dementia at dementia.org.au

Don't be afraid to ask

Individuals and families will express their experiences of dementia in ways that has meaning and significance to them. Not everyone will wish to have their experiences with dementia described in the same way. Where possible, ask that person directly. We can respect the dignity of each individual by respecting that person's wishes regarding use or non-use of certain terms relating to dementia.

Empowering language

It is important to use language that focuses on the abilities (not deficits) of people living with dementia to help people stay positively and meaningfully engaged, and retain feelings of self-worth.

Cultural awareness

Using the term dementia and related words in English may not always be appropriate when talking to people from culturally and linguistically diverse communities or in translation as it may be seen as offensive or disrespectful. Although the understanding of dementia is growing in the Anglo Australian community, there is still a lack of awareness of dementia in many diverse communities. In some cases dementia may be regarded as a mental illness or as a normal part of ageing. Words and phrases that are appropriate in one community may be offensive or of no meaning in another community. It is important to be aware of the cultural background of the person, family or community so that you can use the most appropriate language. It is always advisable to seek guidance from culturally and linguistically diverse communities on appropriate terminology where possible.

When talking about dementia

It is important to know that dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia may affect thinking, communication, memory and in some instances behaviour, and/or the ability to perform everyday tasks and in time it will impact on the person's family, social and working life.

The following terms/phrases are **preferred** when talking about dementia:

- Dementia
- Alzheimer's disease and other forms of dementia
- A form of dementia
- A type of dementia
- Symptoms of dementia

The following terms/phrases **should not** be used:

- Dementing illness
- Demented
- Affliction
- Senile dementia
- Senility
- Going on a journey

Why?

It is important to accurately reflect that dementia is an umbrella for the symptoms and that there are many different forms of dementia, each with its own cause. Senile dementia is an outdated term that used to be used when it was thought that memory loss or other cognitive impairment was a normal part of ageing, rather than being caused by specific types of disorders of the brain.

When talking about people with dementia

People with dementia are individuals first and their diagnosis should not be regarded or referred to as the defining aspect of their life.

The following terms/phrases are **preferred** when talking about a person with dementia:

- A person/people with dementia
- A person/people living with dementia
- A person/people with a diagnosis of dementia

The following terms/phrases **should not** be used:

- Sufferer
- Victim
- Demented person
- Dementing illness
- Dements
- Afflicted
- Offenders, absconders or perpetrators
- Patient (when used outside the medical context)
- Subject
- Vacant dement
- He/she's fading away or disappearing
- Empty shell
- Not all there
- Losing him/her or someone who has lost their mind
- He/she's an attention seeker
- Inmates (referring to people with dementia in care facilities)
- An onion with the layers peeling away
- Slang expressions that are derogatory, for example, delightfully dotty, away with the fairies, got a kangaroo loose in the back paddock, a couple of cents short
- 'They' (talking about all people with dementia rather than the individual)

Why?

Many of the terms listed are demeaning and derogatory. Terms such as 'sufferer' and 'victim' contribute to the stigma surrounding dementia and 'demented person' places the condition before the person. Using the terms person/people with dementia or person/people living with dementia maintains the dignity of the person, emphasises that they are a person first and does not place judgements on the individual because they have dementia.

Often people with dementia are referred to in a group as 'they' which loses sight of the individual and focuses on the condition, using the preferred terms avoids this situation.

When talking about a carer, family member or friend of a person with dementia

People with dementia would prefer the term person/people living with dementia to be used by or to refer to a person diagnosed with dementia rather than used to refer to family, carers and friends.

It is **preferred** that carers, family and friends are referred to as:

- Living alongside (someone/a person/my partner/my mother etc) who has dementia
- Living with/caring for/supporting a person who has dementia
- Living with/caring for/supporting a person with a diagnosis of dementia
- Living with the impact of dementia

When describing someone who is caring for a person with dementia the **preferred** terms/phrases are:

- Family member(s)
- Person supporting someone living with dementia
- Wife/husband/partner
- Child/Son/Daughter
- Parent
- Friend
- Carer or care-giver – not everyone will like to be referred to as a carer. If possible ask what the person's preference is before using this term

In this context the terms apply to someone that is providing unpaid care to a person with dementia, which is different to a professional or paid carer.

When describing the impact of the caring role on someone providing care for a person with dementia the **preferred** terms are:

- Impact of supporting (someone/a person/my partner/my mother etc) with dementia
- Effect of supporting (someone/a person/my partner/my mother etc) with dementia

The following terms **should not** be used when describing the impact of the caring role on someone providing care for a person with dementia:

- Carer burden
- Burden of caring

Why?

Only a person with dementia can truly understand what it is like to live with dementia. Similarly, only a carer knows what it is like to care for a person with dementia.

It is important when referring to someone else in a caring role that you use terms that are emotionally neutral. Everyone has a different experience as a carer and using terms such as 'burden' assumes the role is entirely negative, or that caring for the person with dementia is difficult. Emotionally neutral terms do not make assumptions that the role of the carer is either negative or positive. Of course it is acceptable for a carer to talk about the difficulties they may experience as a result of providing care

When talking about people with dementia under 65

Approximately 7 percent of all people with dementia are under the age of 65.

The **preferred** term/phrase when talking about a person with dementia under 65 is:

- Younger onset dementia

The following terms/phrases **should not** be used when talking about a person with dementia under 65:

- Pre-senile dementia
- Early onset dementia

Why?

Senile dementia is an outdated term that was used when it was thought that memory loss or other cognitive impairment was a normal part of ageing, rather than being caused by disorders of the brain.

Early onset is sometimes used to describe dementia symptoms that occur before the age of 65, but is sometimes also applied to the first symptoms experienced with dementia at any age. To avoid confusion, the term younger onset dementia is seen as preferable to early onset as it specifically refers to any form of dementia where symptoms appear in people under the age of 65.

When talking about the impacts of dementia on the person living with dementia

The symptoms of dementia will be different for each individual, depending on the cause of the dementia and the progression of the disease. It will therefore impact upon people's lives in different ways, of which not all may be negative.

The **preferred** terms when talking about the impacts of dementia are:

- Disabling
- Challenging
- Life-changing
- Stressful

The following terms **should not** be used:

- Hopeless
- Unbearable
- Impossible
- Tragic
- Devastating
- Painful

Why?

Each person will relate differently at different times to their diagnosis and how dementia impacts their life will vary from one person to another. While it is important to be truthful and realistic about the impact of dementia, the words used do not need to be negative, disempowering, pessimistic or frightening.

When talking about the symptoms of dementia

It is important to remember that while there are some symptoms of dementia that will be experienced by most people to some degree, the nature and severity of symptoms can also be very different for each person, and symptoms are likely to change over time.

The following are **preferred** when talking about the symptoms of dementia:

- Describe the symptom itself e.g. memory loss, change in mood or behavior, word finding problems
- Describe the impact it is having e.g. difficulty communicating

When talking about the behavioural and psychological symptoms

Dementia affects people in different ways and changes in the behaviour or emotional state of a person with dementia are common. However in most cases, behavioural and psychological changes are an expression of some need or sensation that the person with dementia is experiencing (for example, frustration, pain, boredom, loneliness, confusion) that they are not able to communicate verbally.

The following expressions and terms are **preferred** when talking about the behavioural and psychological symptoms of dementia:

- Changed behaviour(s)
- Expressions of unmet need
- Behavioural and psychological symptoms of dementia (in a clinical context)

The following terms/phrases **should not** be used when talking about the behavioural symptoms of dementia:

- Behaviour(s) of concern
- Challenging behaviours
- Difficult behaviours

The following terms/phrases **should not** be used when talking about the person with behavioural symptoms of dementia:

- Difficult
- Faded away, empty shell or not all there
- Disappearing
- Aggressor
- Wanderer
- Obstructive
- Wetter
- Poor feeder
- Vocaliser
- Sexual disinhibitor
- Nocturnal
- Screamer
- Violent offender

Why?

It is important to understand that behavioural changes are caused by changes to the brain and can also be affected by an individual's environment (social and physical), health and medication.

Describing the symptom or change suggests that we are defining the person by their symptoms. Regardless of the symptoms the person is experiencing at the time they are always a person first.

When talking about dementia in research or in a medical context

The following expressions and terms are **preferred** when talking about dementia in research or in a medical context:

- Dementia as a condition
- A person/people with dementia
- A person/people living with dementia
- A person/people with a diagnosis of dementia
- A participant (if in a research trial).

The following terms **should not** be used when talking about dementia in research or in medical terms:

- Illness
- Disease (unless speaking about a type of dementia such as Alzheimer's disease)
- Subject
- Case
- PWD (as an abbreviation for a person with dementia)
- PWYOD (as an abbreviation for a person with younger onset dementia).

Why?

In a medical sense dementia is more appropriately described as a condition or set of symptoms unless talking about a specific subtype of dementia such as Alzheimer's disease.

In regards to research it is important to remember you are still referring to a person and the preferred terms should be used.



The following are terms that people with dementia would prefer to be used when talking about dementia and people with dementia in different situations.

Context	Preferred terms	Do not use
Talking about dementia	Dementia Alzheimer’s disease and other forms of dementia A form of dementia A type of dementia Symptoms of dementia	Dementing illness Demented Affliction Senile dementia Senility Going on a journey
Talking about people with dementia	A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia	Sufferer Victim Demented person Dementing illness Dements Afflicted Offenders, absconders or perpetrators Patient (when used outside the medical context) Subject Vacant dement He/she’s fading away or disappearing Empty shell Not all there Losing him/her or someone who has lost their mind He/she’s an attention seeker Inmates (referring to people with dementia in care facilities) An onion with the layers peeling away Slang expressions that are derogatory, for example, delightfully dotty, away with the fairies, got a kangaroo loose in the back paddock, a couple of cents short. ‘They’ (talking about all people with dementia rather than the individual)

Context	Preferred terms	Do not use
A carer, family member or friend of a person with dementia (About themselves)	<p>Living alongside (someone/ a person/my partner/my mother etc) who has dementia</p> <p>Living with/caring for/supporting a person who has dementia</p> <p>Living with/caring for/supporting a person with a diagnosis of dementia</p> <p>Living with the impact of dementia</p>	Person living with dementia
A carer, family member or friend of a person with dementia (About someone else)	<p>Family member(s)</p> <p>Person supporting someone living with dementia</p> <p>Wife/husband/partner</p> <p>Child/Son/Daughter</p> <p>Parent</p> <p>Friend</p> <p>Carer or care-giver – not everyone will like to be referred to as a carer. If possible ask what the person's preference is before using this term</p>	
Impact of caring	<p>Impact of supporting (someone/a person/my partner/ my mother etc) with dementia</p> <p>Effect of supporting (someone/a person/my partner/my mother etc) with dementia</p>	<p>Carer burden</p> <p>Burden of caring</p>
People with dementia under 65	Younger onset dementia	Pre-senile dementia Early onset dementia
The impacts of dementia	<p>Disabling</p> <p>Challenging</p> <p>Life changing</p> <p>Stressful</p>	<p>Hopeless</p> <p>Unbearable</p> <p>Impossible</p> <p>Tragic</p> <p>Devastating</p> <p>Painful</p>
Symptoms of dementia	<p>Describe the symptom itself e.g. reduced vision, hallucinations, difficulty communicating</p> <p>Describe the impact it is having e.g. difficulty communicating</p>	

Context	Preferred terms	Do not use
Behavioural and psychological symptoms of dementia	Changed behaviour(s) Expressions of unmet need Behavioural and psychological symptoms of dementia (in a clinical context)	When talking about the symptoms Behaviour(s) of concern Challenging behaviours Difficult behaviours When talking about the person Difficult Faded away, empty shell or not all there Disappearing Aggressor Wanderer Obstructive Wetter Poor feeder Vocaliser Sexual disinhibitor Nocturnal Screamer Violent offender
In research	Dementia as a condition A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia A participant (if in a research trial)	
Medical	Condition	Illness Disease

Dementia Friends

Key Messages

These key messages are useful when working with media organisations and promoting the wonderful work you are doing. Please become familiar with these key messages and feel free to download from the website and share widely.

Dementia Friends Key Messages

What is the Dementia Friends Program?

- The Dementia Friends program is a national program that aims to transform the way our nation thinks, acts and talks about dementia.
- When registering to become part of the Dementia Friends program, participants can utilise a free online learning tool, through which they can increase their understanding of dementia, and be empowered to do small, everyday things that can make a big difference to a person living with dementia.

What is a Dementia Friend?

- A Dementia Friend is someone who wants to make a positive difference to the lives of people living with dementia through increased awareness and support.
- It means you have increased your understanding of dementia and how small things you can do can help support people with dementia to remain included, accepted and connected with their community.
- A Dementia Friend is someone who understands small acts can make a big difference.
- By having a better understanding of dementia, you are empowered to do small, everyday things that can make a difference to someone with dementia.

For instance:

- Being patient in a shop queue
- Offering assistance if someone appears disoriented or confused
- Allowing extra time for inclusion in a conversation
- Or taking in how the environment might be impacting on someone's ability to focus or engage – noises, bright lights or busy activity can be challenging for people with dementia to filter.

Why the need for a Dementia Friends program?

- An estimated 436,000* Australians are living with dementia. It impacts the individual living with the condition as well as their loved ones who often provide the support and care.
- People living with dementia can find it challenging to participate actively in the community due, in part, to a lack of knowledge or understanding of the condition among the general public and how it can impact people.
- In fact, a recent survey by Dementia Australia found people living with dementia and carers reported experiencing embarrassing situations, feel strongly disconnected, feel less competent and sometimes feel useless.
- By becoming a Dementia Friend, and increasing your awareness of dementia and its impacts, you can help a family member, friend, neighbour or co-worker living with dementia feel accepted, included and involved.
- A little understanding and kindness can go a long way.

How do people become a Dementia Friend?

- Visit dementiafriendly.org.au
- Here you can listen to people with dementia share their stories and be guided through a short education module designed to increase understanding of dementia and its impacts.
- By having a better understanding of dementia, it is hoped people will be empowered to do small, everyday things that can make a difference to someone with dementia.
- Upon completion of the module participants receive a Dementia Friend certificate and you can order a badge.
- Head to dementiafriendly.org.au and start making a difference today.

*as at September 2018

Making it dementia-friendly

A guide to assessing a venue for use of people living with dementia and other disabilities (Revision 2018).

Author Dennis Frost.

Southern Dementia Advisory Group/DA Dementia-Friendly Communities Dementia Advisory Group.

Dennis is a person living with dementia, advisory group member and key Dementia Australia and Dementia-Friendly Community program stakeholder.

Dennis lives in Nowra, NSW, and was diagnosed with frontotemporal dementia shortly after his 59th birthday. He is a driving force in various dementia-friendly communities programs including as inaugural Chair & Chief DAG at Southern Dementia Advisory Group in Kiama, NSW. In 2014 he became involved in this Kiama pilot project which was one of the first begun at a community level in Australia.

With a background in education, Dennis has authored this resource.

Content includes:

- Why assess your venue?
- Challenges people living with dementia may face
- Assessing a venue
- Making changes
- Appendix.

To download this guide, please visit dementiafriendly.org.au/resources



Dennis Frost – Author, Making it dementia-friendly

Southern Dementia Advisory Group/DA Dementia Friendly Communities Dementia Advisory Group



Additional resources

All listed and additional resources are available for download via the resources page of the Dementia-Friendly Communities Resource Hub at dementiafriendly.org.au

Let's talk brochure

The Let's talk brochure was developed by the national Dementia Australia Advisory Committee to set out communication tips for talking to people living with dementia.

The Advisory Committee hopes it will be used to help family, friends, carers, service providers, health professionals and the general community.

The Advisory Committee is made up entirely of people living with dementia. The committee's role is to advise and determine the priorities of people living with dementia in regards to consumer advocacy, new policy, service delivery and program development. The committee is supported by Dementia Australia.

Please visit dementiafriendly.org.au/resources

Environmental Design Resources – Dementia Training Australia

The goal of this collection of resources is to support those who wish to improve environments for people living with dementia. A good environment can, almost by itself, reduce confusion and agitation, improve wayfinding and encourage social interaction. On the other hand, a poor environment increases confusion and behaviour that causes distress to people with dementia and others and will eventually reduce staff to a state of helplessness, in which they feel that nothing can be done.

Please visit dementiafriendly.org.au/resources/environmental-design-resources

Dementia-Friendly Home app

Developed by Dementia Australia, the Dementia-Friendly Home app provides simple ideas to enable people living with dementia to remain in their homes for longer.

Based on ten Dementia Enabling Environment Principles, (enablingenvironments.com.au/dementia-enabling-environment-principles.html) this app recommends practical changes that prompt carers to think about how the home can be changed in a way that may assist the person living with dementia.

Many of the app suggestions are small, inexpensive ideas, such as placing labels with pictures on cupboard doors. More significant changes include installing motion sensors that turn lights on and off when people walk through the house and changing busily patterned wall or floor coverings.

The app is available directly from the App Store or Google Play Store. Learn more via dementia.org.au/dementia-friendly-home-app

Dementia Enabling Environment Project (DEEP)

Developing an enabling environment for a person living with dementia can make a significant difference to independence, quality of life and well-being.

Well-designed environments, planned with cognitive impairment in mind, can help maintain abilities and provide meaningful engagement by providing essential prompts, accessibility and reduce risks to support a person with dementia. Poorly designed environments can be confusing, disorienting, disabling and even dangerous for those living with dementia.

The DEEP Virtual Information Centre provides practical tips, guides and resources to help make the places where we live more dementia enabling. It includes:

- Dementia Enabling Environment Principles (based on the work of Prof. Richard Fleming and Kirsty Bennett, University of Wollongong) enablingenvironments.com.au/dementia-enabling-environment-principles.html
- Adapting a house
- Care environments
- Gardens and nature
- Public buildings.

Please call Centre for Dementia Learning to discuss organisation environmental audits, 1300 DEMENTIA (1300 336 368). Or, visit enablingenvironments.com.au

Dementia Australia education and training

Dementia Australia offers a range of education and training services for people living with dementia, their family and friends, health professionals and care workers, community volunteers, members of the community and carer support group leaders.

For information regarding training and education available through your local Dementia Australia office, please visit dementia.org.au/learning or contact the Dementia Helpline on 1800 100 500.

Dementia Training Australia

Dementia Training Australia (DTA) is funded by the Federal Government to provide dementia education and training across Australia, combining the expertise of five universities and Dementia Australia to deliver a coordinated national approach to dementia training for individuals and organisations.

The aim of DTA is to improve the care and well-being of people living with dementia, and the well-being of staff delivering their care, by providing or brokering nationally consistent, high-quality knowledge translation services to aged and health care staff, managers and other professionals.

Please visit dta.com.au

University of Tasmania – Understanding Dementia Massive Open Online Course (MOOC)

The University of Tasmania's MOOC, Understanding Dementia, is a nine-week online course that builds upon the latest international research on dementia. The curriculum draws upon the expertise of neuroscientists, clinicians and dementia care professionals in the Wicking Dementia Research and Education Centre. It is free and anyone can register.

Please visit mooc.utas.edu.au/courses

University of Tasmania – Bachelor of Dementia

The Bachelor of Dementia Care is online and available nationally and internationally to students looking to specialise in the aged care industry and in the provision of care for people living with dementia. It is completed entirely online with no exams, face-to-face study, or workplace assessment component.

It will prepare you for a range of career paths in the aged care industry, as well as for entry to graduate programs in medicine and allied health, which can lead to a wide range of career paths throughout the public and private health sector.

Please visit utas.edu.au/courses/chm/courses/m3s-bachelor-of-dementia-care

Information about dementia

How to support people living with cognitive impairment

This is an information sheet designed to help support people within the community who might be living with dementia or other forms of cognitive impairment.

What is dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia can happen to anybody, but it is more common after the age of 65.

In 2018, dementia affects an estimated 436,000 Australians with this number set to rise to more than 1.1 million by 2058.

There are many types of dementia but they are all diseases of the brain which invariably result in difficulties with:

- Memory
- Everyday tasks, like handling money
- Communication, such as language or word finding
- Perception.

Dementia is a progressive terminal disease with mild symptoms in the early stages of the disease which generally worsen over time. Dementia affects everyone differently, and in fact, not everyone you meet may have any visible symptoms.

Why do I need to know this?

The growing number of people with dementia will mean the number of your customers with dementia will also increase.

Information contained in this resource provides basic information that can help you to provide a better service to people living with dementia.

Everyone experiences dementia in different ways, and no two people are the same. What is a problem for one person, may not be for another, and visa-versa.

How do I know if someone has dementia?

There is no easy way to tell if a person has dementia. Most people living with dementia are over 65 years but some are younger. A person with dementia may appear confused and disorientated or they may lack insight. Some people may appear to have no external symptoms at all. There is no singular presentation as the condition exhibits across a range of domains.

Some people living with dementia will tell you if they are having problems, and how you can help, while others may prefer to keep their diagnosis private.

The most common signs of dementia are memory loss, language difficulties and confusion. You might notice a customer saying or doing things which signal they are having problems that might be caused by dementia.

These may include:

- Looking or saying that they are confused or lost
- Appearing to be searching for something they can't find
- Appearing unsure of what to do next
- Problems handling money or knowing how to use their credit card. They may also have registered to continue signing their credit card
- Difficulty understanding self-service facilities
- Difficulty with speech or finding the right words
- Appearing to have problems understanding what you are saying
- Forgetting to pay for things they've picked up.

It is important to remember there are a range of other reasons why people might have these problems that are not related to dementia or memory problems.

How can I communicate better with a person living with dementia?

If you have good “people skills” you already have much of what you need to provide a good service to people living with dementia. Kindness, patience, common sense, respect, avoiding stress, using good communication skills and a smile go a very long way.

People living with dementia have told us that some key principles of good communication are to:

- Treat the person with dignity and respect.
- Don't question the diagnosis; the symptoms of dementia are not always obvious.
- Talk to the person with dementia, instead of their carer, family member or friend.
- Don't prejudge their level of understanding.
- Make eye contact and speak clearly. Use short sentences with one idea at a time.
- Avoid jargon.
- Keep questions simple. It is often easier for a person living with dementia to answer direct questions rather than open-ended questions.
- Reduce distractions such as noise and lights if possible.
- If you play background music in your store, keep the volume low.
- Be patient and understanding.
- Break information down into smaller chunks.
- Use clear and simple signage with large plain font.



Frequently asked questions – How can I help?

Q: What can I do if I see a person who looks lost or confused, or looks like they don't know what to do next?

A: Approach the person in a friendly open manner, and ask "can I help?" It really is that simple, and for many people living with dementia, this will be all they need, and will be able to explain exactly how you can help.

Q: What can I do if people are appearing to have problems handling or understanding their money or how to use their card or using self-service facilities?

A: Again, the first approach should be to ask if you can help. You can also:

- Tell them to take their time – there is no hurry.
- Offer to run the items through self-service or show them how to do it.
- Ask if they would like to sign for their purchase if they can't remember their PIN.
- Offer to keep their shopping to one side so that they can come back and collect it when they are able.

Q: What can I do if the person has trouble understanding what I am saying?

A: Some people living with dementia can develop problems with understanding what is said to them, especially if they feel stressed or hurried, or if there is a lot of background noise and distractions.

- Take your time – speak clearly and match the speed in which they speak.
- Try to make only one point at a time.
- Say things more simply if you need to, but do not infantilise your language or tone.
- Use good eye contact.
- Try saying things another way.

Q: What can I do if someone appears to have forgotten to pay for something?

A: This is difficult. While someone may have forgotten to pay, they might equally be engaged in theft, and your safety is the most important thing. If you know the person, and you know that they have dementia, then you can simply ask if you can help, and if they would like to pay. This will often be all you need to do.

On occasion, people living with dementia may not understand that they need to pay or perhaps feel that they shouldn't. Some businesses, if they know the person and/or their carer, have totalled up the value of the items and asked the carer to arrange for payment.

If you do not know the person and feel uncertain as to why they have not paid for something, then your usual policy on theft should apply. If you are concerned that the person may have cognitive impairment, you should alert the police or anyone else involved that cognitive impairment may be a contributing factor.

Q: What if this advice does not work and I am unable to help the person who seems confused?

A: Ask the person if there is anyone you can contact who might be able to help. If so, call them. If none of this works, and the person appears to need help, call your manager for help. If you are the manager, or you are working alone, depending upon the nature of your business and location, you could call emergency services or the police for assistance.

Responding to questions asked at dementia-friendly promotions or events

A growing awareness of dementia has made people in the community very sensitive to moments when they forget things.

Individuals may express distress or concern

about their memories, previous head injuries, concussion, or when they have been unconscious, and so on. There are two important things to share after acknowledging these concerns:

1. The importance of talking with their GP.
2. Suggesting they phone the National Dementia Helpline (1800 100 500) to discuss his or her concern.

Talking with people about the National Dementia Helpline may be the appropriate course of action for many personal questions. People who have a family member living with dementia may feel emotions, such as grief, anger, depression, or guilt, and have no one to talk to about what he or she is feeling.



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National Dementia Helpline 1800 100 500
www.dementia.org.au

