# CREATING DEMENTIA-FRIENDLY COMMUNITIES FUSIFIES



The Alzheimer's Australia Dementia Friendly Toolkit was compiled utilising a range of international resources on dementiafriendly communities and age-friendly communities.

# CREATING DEMENTIA-FRIENDLY COMMUNITIES A TOOLKIT: INTRODUCTION

# What is Dementia?

Dementia currently affects more than 332,000 Australians. There are many types of dementia but they are all diseases of the brain which invariably result in:

- Difficulties with memory
- Difficulties with everyday tasks, like handling money
- Difficulties with communication, such as language or word finding
- Difficulties with 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.

### 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. For people with younger onset dementia, this should mean the option of being supported to stay at work, like any other disabled person, as being dementia friendly is not only about social engagement. Each dementia-friendly community will look different, but may include:

- Businesses that provide accessible services to people with dementia including having 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 opportunities for people with dementia
- Memory cafes for people with dementia and their families

- Choirs, walking groups, sporting clubs and social groups that are welcoming and inclusive of members 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.

# Why do we need to be dementia friendly?

The growing numbers of people living with dementia will require 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. By 2020, it is estimated that there will be around 400,000 with dementia and close to 900,000 people by 2050.

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

### What do people with dementia say?

In 2014, Alzheimer's Australia conducted its first national survey of people with dementia identifying priorities for tackling the stigma and social isolation associated with dementia in the community. People with dementia indicated the need for changes to our communities to make them more dementia friendly and to support people with dementia to continue to live well and to be involved in the things they enjoyed before a diagnosis.



People with dementia identified the following priority areas in creating dementia friendly communities:

- 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
- Access to appropriate health and care services to support them to continue to live at home for as long as possible
- 5. Access to affordable and convenient transportation options
- 6. Improved physical environments including appropriate signage, lighting and colours

### **Dementia Friendly Toolkit**

The Dementia Friendly Toolkit aims to provide you with the information you will need to make your community or business more dementia friendly.

Information contained within the kit includes:

- Social and environmental checklists
- Guidelines for organisations to become dementia friendly
- Information for staff on how to effectively communicate with people with dementia
- Information on existing resources which could be used to increase staff awareness about dementia
- A guide to how to create a Dementia Alliance and developing an action plan to creating a dementia-friendly community
- A template letter to write to your local MP to support the development of dementia-friendly communities

# Further tools and resources will be added to this toolkit in the coming months.

#### How can I be involved?

We would like to invite people with dementia, their family members, friends or carers, people from service clubs, shopkeepers, council workers to be part of the project... in fact anyone who is interested in making their community more dementia friendly can get involved! For more information, to see how you can be involved or to share your story please contact: dementiafriendly@alzheimers.org.au or phone 02 6278 8934.

Alzheimer's Australia would like to acknowledge Innovations in Dementia in informing the development of this resource.



# **WORKING TOWARDS**



**EMENTIA FRIENDLY** 

# THE DEMENTIA-FRIENDLY SYMBOL

# Background

As part of Dementia Awareness Month 2014 Alzheimer's Australia will release a dementia-friendly symbol in addition to the guidelines in this kit for how organisations can become recognised as being dementiafriendly. The symbol was developed and endorsed by people living with dementia as a national symbol for raising awareness about cognitive impairment. The objective is for the abstract symbol to become recognisable across Australian communities to denote a business or community that is dementia friendly.

Initially in 2014 our goal is to target use of the symbol in a small number of organisations and communities where we are already doing pilot work (e.g. Kiama, Port Macquarie, Perth). This will enable us to test and refine the approach to use of the symbol and how it is monitored before a wider roll out.

### The use of the dementia-friendly symbol

The symbol will initially be used in organisations working towards becoming dementia friendly. These organisations will make the commitment to be more aware of the needs of people with dementia and aim to provide an improved service. Displaying the dementiafriendly symbol will signify that the organisation has submitted an approved dementia-friendly action plan. The action plan will address the essential principles outlined in the Guidelines for dementia-friendly organisations.

The guidelines are available as part of the Dementiafriendly Business Toolkit available at dementia.friendly. org.au. For people living with dementia, seeing the symbol displayed, will mean than an organisation has staff who are specially trained and have an understanding of dementia.

In the longer term, the symbol will be used in a variety of ways, always with the involvement of people with dementia.

For more information about the dementia friendly symbol:

Please contact Alzheimer's Australia at dementiafriendly@alzheimers.org.au or Ph. 02 6278 8934



# RESOURCES FOR INCREASING STAFF AWARENESS ABOUT DEMENTIA

People with dementia may need extra support or understanding when they are interacting with staff in the community. The experiences of the person with dementia in public situations will vary but may include:

- Have problems remembering what they are doing
- Have difficulties in communicating clearly
- Have problems handling money
- Have problems navigating in complex or confusing environments
- · Language and word finding impairments
- They may appear to have no symptoms at all

How staff respond to people experiencing these issues can make a real difference. People with dementia tell us repeatedly that it is the attitude of those they encounter in their communities which has the biggest impact on their lives in their community.

# What do staff need to know?

A basic understanding of the impact of dementia and how to support and communicate with people who have dementia can make a huge difference both to the experience of the customer and to the staff member/s involved.

The amount of training staff need will depend upon their role. However, there are likely to be some similar themes and needs across all public-facing situations:

- Why it matters
- · How to recognise that people may be having problems
- How to respond to people who may be having problems, regardless of whether there are visible symptoms of dementia
- How to communicate more effectively with people with memory problems or cognitive impairment like confusion and language difficulties
- What to do if someone needs help

This document outlines a range of resources (mostly free) which are already available to assist staff in knowing how to respond to a person with dementia.

# **EXISTING RESOURCES**

#### **Dementia Language Guide**

Alzheimer's Australia has developed a 'Dementia Language Guide' alongside people living with dementia. The aim of the guide is to promote the consistent use of appropriate inclusive and non-stigmatising language when talking about dementia.

The words used to talk about dementia can have a significant impact on how people view or treat people 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.

# Further information about the guide can be obtained from: www.dementiafriendly.org.au

#### **Is it Dementia Training Resource**

The 'Is it Dementia' national training resource was produced by Alzheimer's Australia South Australia and was launched nationally in May 2013. The resource comprises a suite of 12 short films created by award winning filmmakers highlighting how dementia can impact the everyday work lives of Australians. The resource contains films, factsheets and facilitator guide questions for a range of industries including banking, transport, emergency services and retail. The resource aims to raise awareness of dementia and educate employees working in industries on the signs of dementia and considerations in effectively communicating with a person with dementia.

Further information about the resource can be obtained from: http://isitdementia.com.au/

UNDERSTAND ALZHEIMER'S

**EDUCATE AUSTRALIA** 

FIGHTDEMENTIA.ORG.AU

#### **Talk to Me Brochure**

The Talk to me brochure was developed by the Alzheimer's Australia Dementia Advisory Committee to set out good communication tips for talking to people with dementia.

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

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

# A copy of the brochure can be obtained from: http://www.fightdementia.org.au/common/files/ NAT/TalkToMe\_Brochure\_FoldedDL\_HR.pdf

### **Dementia Enabling Environment Project (DEEP)**

Alzheimer's Australia is working to address the gap between existing research about dementia friendly environments and current design practices via a project which is funded through the Alzheimer's Australia National Quality Dementia Care Initiative (NQDCI). This national project aims to translate research into practice in the area of enable environments for people with dementia. The project website serves as a clearinghouse for information on:

- Resources
- Environmental audit tools
- E-newsletters
- Workshops for professionals and families
- A national library lending resource

Further information about the resource can be obtained from: http://www.enablingenvironments.com.au/

# **Building Dementia and Age-Friendly Neighbourhoods Report**

This paper identifies features that can help create optimum dementia and age-friendly outdoor environments. Those features have been compiled into the Alzheimer's Australia NSW Dementia-Friendly Outdoor Design Checklist, which is intended to help guide planners and policy makers when developing Community Strategic Plans, Development Control Plans (DCPs) and other planning instruments.

The paper also examines the literature, discusses the issues and makes recommendations for policy change to help ensure people with dementia and their carers can remain living in and connected to their neighbourhoods for as long as possible.

A copy of the report can be obtained from: http://www.fightdementia.org.au/ common/files/NSW/20110803-NSW-PUB-DementiaFriendlyNeighbourhoods.pdf

# **Dementia Training Study Centres (DTSC)**

The DTSC aims to improve the quality of care and support provided to people living with dementia and their families through providing development opportunities for existing and future dementia care health professionals.

The DTSC provides a dedicated range of courses, workshops, seminars, scholarships, support, and curriculum development that translates contemporary knowledge into practical, effective approaches to helping people living with dementia and their families.

Further information about DTSC can be obtained at: http://www.dtsc.com.au/



# University of Tasmania- Understanding Dementia MOOC

The University of Tasmania's Massive Open Online Course (MOOC), Understanding Dementia, is a 9-week online course that builds upon the latest in international research on dementia. It's free and anyone can register. The curriculum draws upon the expertise of neuroscientists, clinicians and dementia care professionals in the Wicking Dementia Research and Education Centre.

### **University of Tasmania- Bachelor of Dementia**

The Bachelor of Dementia Care is fully 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 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.

### **Alzheimer's Australia Education and Training**

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

# To obtain further information regarding training and education available through your local Alzheimer's Australia office, please contact the Dementia Helpline on 1800 100 500.

Alzheimer's Australia would like to acknowledge Innovations in Dementia in informing the development of this resource.



# GUIDELINES ON THE DEVELOPMENT OF DEMENTIA-FRIENDLY ORGANISATIONS

# BACKGROUND

Dementia is a progressive, degenerative condition that affects more than 332,000 Australians. Although dementia is more common in older people, there are more than 24,700 Australians under the age of 65 who have dementia. Dementia causes a gradual change in cognitive function and affects people in different ways.

Most people with dementia continue to live in the community. With support, many people with dementia are able to remain active and participate in many of the same activities they did before they received a diagnosis.

Often after a diagnosis of dementia, people experience social isolation, stigma and discrimination. Friends and even family members may stop visiting or calling because they feel unsure of how to interact with a person who has a cognitive impairment. Lack of awareness in the community can lead to unintentionally mistreating the person with dementia.

Retail staff, transport workers and community groups are often unaware of the additional needs of a person with dementia or how to communicate with them. Some people can experience significant delays in getting a diagnosis of dementia, so service staff need to be aware of the needs of people with cognitive impairment whether or not they have an official diagnosis.

Organisations can support people with cognitive impairment by providing services that are accessible to them.

# WHAT IS A DEMENTIA-FRIENDLY ORGANISATION?

Successful businesses are good communicators and are customer focused. Dementia-friendly organisations are no different. They are businesses or other organisations (including local government and community services) that travel the extra mile to make changes and improvements to their services, procedures and environment to better meet the needs of people living with dementia. Dementia-friendly organisations take the simple steps necessary to improve their services such as providing education and training for staff on how to communicate with a person who has dementia.

# WHY BECOME DEMENTIA FRIENDLY?

People with dementia deserve the same service and human rights as all other Australians, with full inclusion in their community. Your organisation probably already has many customers who are living with dementia, and you are likely to have many more in the future. Becoming dementia friendly means you can provide better services to your existing customers as well as better meet the needs of people with dementia.

# EXAMPLES OF DEMENTIA-FRIENDLY ORGANISATIONS

Dementia-friendly organisations will look different depending on the type of business and services provided. The requirements to become dementia friendly are different depending on whether you are a small organisation or a larger business.

- A dementia-friendly bank could identify staff who have had dementia training and who can provide a better service to people with cognitive impairment. They could also examine their physical environment and signage to ensure that it is meeting the needs of people with dementia.
- A dementia-friendly retail store could examine their signage and layout to ensure it is meeting the needs of people with dementia. They could also decide to have a staff member undertake dementia training.
- A dementia-friendly community group could support a volunteer program for people with dementia to promote social engagement while also raising community awareness of dementia.

UNDERSTAND ALZHEIMER'S

**EDUCATE AUSTRALIA** 

FIGHTDEMENTIA.ORG.AU

**CREATING DEMENTIA-FRIENDLY COMMUNITIES - BUSINESS TOOLKIT** 

- A dementia-friendly bowls club could make allowances for members who have difficulty remembering the rules of the game by having a buddy program to support members with dementia.
- While there are differences in what constitutes dementia friendly for different organisations, there are a number of common principles that need to be considered.

# WHAT ARE THE ESSENTIAL PRINCIPLES OF A DEMENTIA-FRIENDLY ORGANISATION?

From talking to people with dementia, we know that the following principles are fundamental for an organisation to be considered dementia friendly.

- Keep the needs of people with dementia at the centre of becoming a dementia-friendly organisation;
- Commit to being more inclusive and aware of the needs of people living with dementia;
- Staff have awareness and understanding of dementia and strategies for good communication with people who have dementia. This can be achieved through education and training activities for staff, including information on good communication principles for people who have dementia;
- Review the physical environment to ensure it is accessible and appropriate for people with dementia. A continuous improvement plan may be made to address any concerns (e.g. changes to signage, lighting);
- Review business documentation including forms and publications to ensure they use clear, straightforward language and appropriate design; and
- Plan a review and continuous improvement cycle for dementia friendly and build it into organisational planning.

The requirements to be recognised as working towards becoming dementia friendly are based on the organisation's size. Each organisation may take a different approach to implementing these principles, tailored to the individual requirements and circumstances of that business or organisation.

### **Involvement of people with dementia**

Organisations that commit to becoming dementia friendly need to recognise the needs of people with dementia. Through consultations with people living with dementia, businesses can identify the aspects of their organisation that support or are barriers for people living with dementia. If you would like assistance getting in touch with a person living with dementia to help with your planning, please contact Alzheimer's Australia at dementiafriendly@alzheimers.org.au.

### Commitment

Becoming a dementia-friendly organisation requires an organisation-wide commitment, including from senior management. The importance and benefits of being a dementia-friendly organisation should be communicated to all staff. Dementia friendly changes could be the responsibility of one enthusiastic team member who wants to make a difference, or could be broadened to involve an internal working group. Organisations would be asked to agree to a commitment statement developed by Alzheimer's Australia as an initial step.

#### **Awareness and understanding**

A key part of becoming a dementia-friendly organisation is to increase staff awareness and understanding about dementia so they are better able to assist people who have a cognitive impairment. Organisations can achieve this in a number of ways including through education and training activities on communicating with a person who has dementia, and including information about dementia in induction and orientation packs.



Alzheimer's Australia has a range of resources and education and training activities that can be provided to support staff. Organisations can access an online training resource called "Is It Dementia?" which is a collection of short videos highlighting some of the major factors for people living with dementia. The resource is available at: www.isitdementia.com.au.

Organisations can also read the 'Talk to me' brochure, which provides insights on the best way to communicate with people with dementia. The brochure is available at: http://www.fightdementia.org.au/common/files/NAT/ TalkToMe\_Brochure\_FoldedDL\_HR.pdf

### **Physical environment**

The physical environment, including signage and layout can have an impact on the experiences of a person with dementia. All organisations working towards becoming dementia friendly should review their environment. Simple changes may be all that is required to ensure the physical design of the office is appropriate for a person with dementia. Clear signage, and being conscious of background noise and use of contrasting colours are simple strategies that organisations could adopt. The Dementia Enabling Environments Program (DEEP) website provides resources and information on dementiafriendly design: http://www.enablingenvironments.com. au/. Alzheimer's Australia is developing an audit tool for dementia-design in public spaces that will be available by October 2014.

# **Business documentation**

Business documentation and forms can be confusing for people with cognitive impairment. As part of a dementiafriendly approach, documents that might be relevant to your customers with dementia should be reviewed and if possible simplified to use straightforward and clear language.

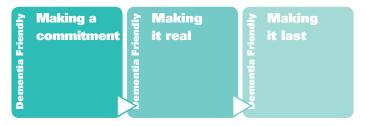
# **Review and continuous improvement**

A regular review of actions towards becoming dementia friendly is necessary to ensure the sustainability and relevance of the dementia friendly concept for the organisation. Organisations will be required to revisit their action plan every 12 months to continue to be recognised as a dementia-friendly organisation.

# HOW TO BECOME A DEMENTIA-FRIENDLY ORGANISATION

There are three stages for being recognised as a dementia-friendly organisation. The requirements in each stage vary depending on the size of the organisation.

These three stages are defined below.



# Stages and requirements for dementia-friendly organisations

The requirements under each stage of working towards becoming a dementia-friendly organisation are dependent on the size of the organisation. Organisations can elect as to whether they see themselves as a small or large organisation and which set of guidelines suit their circumstances.



#### **Making a commitment**

### **Small organisations**

- · Discuss becoming dementia friendly with staff
- Ensure that you have staff support and involvement in the concept, including from the owner and management
- Register the organisation by contacting Alzheimer's Australia at dementiafriendly@alzheimers.org.au
- Once registered Alzheimer's Australia will provide a briefing pack of information about becoming dementia friendly. This will include a template version of the dementia-friendly statement, which details the commitments as well as lists some of the key activities your organisation needs to consider in the initial 12-month period

### Large organisations

- · Discuss becoming dementia friendly with staff
- Ensure that you have all levels of management within the organisation committed to this initiative, including at the CEO and Board level
- Register the organisation by contacting Alzheimer's Australia at dementiafriendly@alzheimers.org.au
- Once registered Alzheimer's Australia will provide a briefing pack of information about dementia friendly. This will include a copy of the commitment statement and an action plan template
- Organisations are encouraged to include people living with dementia in the preparation of the action plan to ensure relevant and meaningful action items are detailed
- The signed commitment should be completed and returned to Alzheimer's Australia

#### **Making it real**

### **Small organisations**

- Consider the suggested actions provided by Alzheimer's Australia and how they could relate to your business
- Talk to your staff about what strategies they will work towards
- Consider how people living with dementia can support the organisation to become dementia friendly
- Complete and return the signed dementia-friendly statement, which includes some key areas of action, to Alzheimer's Australia
- The dementia-friendly statement will be reviewed and endorsed by a state-based Alzheimer's Australia consumer group made up of people living with dementia, or the National Alzheimer's Australia Dementia Advisory Committee
- Once the statement is endorsed, or the requested changes have been made, then the dementia-friendly symbol will be provided to your organisation to display and promote your dementia-friendly status

### Large organisations

- The organisation should develop its action plan with input from people living with dementia.
- Along with firm actions addressing some of the essential principles of a dementia-friendly organisation, the action plan can also include innovative ideas to trial. Examples to consider could be investigating the possibility to provide people with dementia the opportunity to volunteer, or creating avenues of social engagement and inclusion for those living with dementia
- A plan for education and training activities for staff should be developed



- The action plan is submitted to Alzheimer's Australia for feedback and endorsement of either a state-based Alzheimer's Australia consumer group or the National Alzheimer's Australia Dementia Advisory Committee
- Once the action plan is endorsed, the Dementiafriendly symbol will be provided to your organisation to display and promote your dementia-friendly status

# **Making it last**

#### **Small organisations**

- Organisations must review their dementia-friendly status on an annual basis including providing a brief summary of how it has achieved the actions outlined in the dementia-friendly statement.
- This reflection provides an opportunity for the organisation to set new strategies and priorities for the next 12-month period.
- The summary will be reviewed by either a state-based Alzheimer's Australia consumer group or the National Alzheimer's Australia Dementia Advisory Committee.

#### Large organisations

- Organisations should review their dementia-friendly activities as an active part of regular business operations. For example, it could be added as a standing item at staff meetings.
- Alzheimer's Australia will review the organisation's dementia-friendly status on an annual basis. The review process involves providing advice to Alzheimer's Australia on the progress and achievements in the action plan and setting new priorities and areas for action.
- The reporting on the action plan must be provided to Alzheimer's Australia by email at dementiafriendly@ alzheimers.org.au

- The updated plan will be reviewed either by the statebased Alzheimer's Australia consumer group or the National Alzheimer's Australia Dementia Advisory Committee.
- Once an action plan has been developed and reviewed, Alzheimer's Australia will provide an updated symbol for use over the next 12 months.

# FEEDBACK

Organisations working towards becoming dementia friendly make a commitment to be more aware of the needs of people living with dementia, and deliver a better service to help them remain active and engaged within the community. The views and experiences of people living with dementia are important to Alzheimer's Australia and we encourage people with dementia to tell us about their experiences interacting with organisations that are recognised as being dementia friendly. All feedback should be provided by email or post to: dementiafriendly@alzheimers.org.au

Dementia-Friendly Organisations Manager/Policy Team 1 Frewin Place Scullin ACT 2614

Alzheimer's Australia reserves the right to revoke permission to use the dementia-friendly symbol at any time.

This dementia-friendly action plan will be reviewed by either a State based consumer committee or the National Alzheimer's Australia Dementia Advisory Group (AADAC). These committees may seek clarification or provide feedback on this action plan to ensure it is realistic and targeted at achieving meaningful outcomes for people with dementia.

# DEMENTIA-FRIENDLY ORGANISATION ACTION PLAN TEMPLATE

This dementia-friendly action plan will be reviewed by either a State based consumer committee or the National Alzheimer's Australia Dementia Advisory Group (AADAC). These committees may seek clarification or provide feedback on this action plan to ensure it is realistic and targeted at achieving meaningful outcomes for people with dementia.

Please list one to two action items for each essential principle

Please forward the completed Action Plan to dementiafriendly@alzheimers.org.au

Who we are	Description of the organisation or business, including key stakeholders, numbers of employed staff and location of business operations		
Our commitment to being dementia friendly	What is the organisation's vision for being dementia friendly. Provide details how being dementia friendly relates to your business or organisation.		
Our dementia-friendly action plan	Explain who has been involved in the development of this plan		
Essential Principle	People with dementia are involved in the process of becoming dementia friendly Possible action: A person with dementia is identified to assist the dementia-friendly process		
Action	Responsibility	Timeline	Progress
List the possible actions that could be taken to achieve this aim	Who will be responsible	When will this action be completed by	Progress to date
1.			
2.			
ESSENTIAL	<b>Commitment</b> Possible action: Becoming a dementia-friendly organisation is discussed by Board of Directors		
PRINCIPLE			
Action	Responsibility	Timeline	Progress
	<b>Up-skilling staff</b> Possible action: provide der	nentia awareness education a	and training to staff
PRINCIPLE		nentia awareness education a Timeline	and training to staff Progress
PRINCIPLE	Possible action: provide der		
PRINCIPLE	Possible action: provide der		
PRINCIPLE	Possible action: provide der		
ESSENTIAL PRINCIPLE Action ESSENTIAL	Possible action: provide der Responsibility Review of the Physical	Timeline  Environment	Progress
PRINCIPLE Action ESSENTIAL	Possible action: provide der Responsibility Review of the Physical	Timeline	Progress
PRINCIPLE Action	Possible action: provide der Responsibility Review of the Physical	Timeline  Environment	Progress
PRINCIPLE Action ESSENTIAL PRINCIPLE	Possible action: provide der Responsibility Review of the Physical Possible action: Use the der	Timeline Environment nentia-friendly audit tool to rev	Progress iew the physical environmen
PRINCIPLE Action ESSENTIAL PRINCIPLE	Possible action: provide der Responsibility Review of the Physical Possible action: Use the der	Timeline Environment nentia-friendly audit tool to rev	Progress iew the physical environmen



ESSENTIAL PRINCIPLE	Business documentation Possible action: Establish a small working group to review business forms and documentation to incorporate dementia-friendly concepts		
Action	Responsibility	Timeline	Progress
ESSENTIAL Principle	<b>Review and Continuous Improvement</b> Possible strategy: Incorporate dementia-friendly status into yearly review processes		
Action	Responsibility	Timeline	Progress
OPTIONAL	Other Dementia-friendly to include	/ action items that your o	organisation would like
Action	Responsibility	Timeline	Progress
ORGANISATIONAL CONTACT FOR DEMENTIA FRIENDLY			
Please provide contact detai	Please provide contact details for the primary contact for dementia friendly		

This plan has been reviewed by the Alzheimer's Australia Dementia Advisory Committee, with the following outcome:

Dementia-friendly status approved	Revision to the action plan required

Signature of Committee member

Date



# CREATING DEMENTIA-FRIENDLY COMMUNITIES CHECKLISTS

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 things you and your community can do to help people with dementia to remain engaged in the community in a meaningful way. This can be done by ensuring that the physical environment is easy to navigate and safe for people with dementia. Many of these suggestions are things that will benefit all members of the community. 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	Adequate and evenly distributed street lighting to assist those with dementia and lower visual acuity
Outdoor seating is safe, well maintained and adequate in number	Level changes are clearly marked and well lit with handrails and non-slip, non-glare surfaces
Undercover areas in parklands are provided to ensure accessibility in all weather conditions	Buildings are well-signed outside and inside, with sufficient seating and toilets, accessible elevators, ramps, railings and stairs, and non-slip floors.
Footpaths are wide, level where possible, non-slip, well maintained and free of obstructions	Indoor and outdoor public toilets are well-maintained, clean, accessible and adequate in number with appropriate signage
<ul> <li>Bicycle pathways are separate from footpaths and other pedestrian walkways</li> </ul>	Bus shelters are enclosed and have adequate seating
Adequate number of pedestrian crossings which are functional for people with different levels of disability with non-slip markings	Street clutter including excessive signage, music, advertisements and bollards are minimal
Pedestrian crossings have visual and audio cues and provide sufficient crossing time	Background noise is minimal with acoustic barriers such as grass rather than hard surfaces, trees, hedges and fencing in place
☐ Visual landmarks are in place to assist way-finding such as garden beds, murals, water fountains/features,	Signs have large graphics and symbols in clear colour contrast to the background, preferably dark lettering on a light background
Building entrances buildings are clearly visible and obvious	□ Signs have non-glare lighting and non-reflective coverings

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

**UNDERSTAND ALZHEIMER'S** 

**EDUCATE AUSTRALIA** 

FIGHTDEMENTIA.ORG.AU

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	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 included in community initiatives and projects to provide their input and feedback	People with dementia are recognised for their past and ongoing contributions to their community
People with dementia are supported to speak at conferences and local events about dementia	Dementia awareness activities and events are held to increase community knowledge and understanding of dementia
Community events and activities are held at convenient times during the day for people with dementia	Local support groups for people with dementia, their carers and family members are available e.g. Memory Cafés
Community events and activities are held that can be attended either alone or with a carer	People with dementia are regularly consulted by public, volunteer and commercial services on how best to serve them
Affordable transportation options are available to people with dementia	Hobby and interest groups provide support to assist people with dementia to remain engaged e.g. choir, walking groups
Information about community events and activities are readily provided including details regarding accessibility of facilities and transportation options	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
Venues for community events and activities are conveniently located, accessible, well-lit and easily reached by public transport	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	Qualities of people with dementia who are employed are well promoted and recognised	
Flexible and appropriately paid opportunities for people with dementia to continue working, or become employed are promoted	Volunteering opportunities are offered and promoted by communities, businesses and organisations to promote social engagement	
Decision-making bodies in public, private and voluntary sectors encourage and facilitate membership of people with dementia	Training and education opportunities for people with dementia are provided and promoted	
Employment programs to support people with dementia undertake a range of activities are provided and promoted	Adequate support is provided by training and education institutions to people with dementia undertaking further study	
Workplaces are adapted to meet the physical needs of people with dementia	People with dementia are consulted in order to ascertain who they can best be supported in the workplace and education and training institutions	
Training and education opportunities for people with dementia are provided and promoted	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.



# INFORMATION ABOUT DEMENTIA FOR FRONT LINE STAFF

# How to help customers with cognitive impairment

This is an information sheet aimed at helping you to support customers who might have dementia or other forms of cognitive impairment.

### What is dementia?

Dementia is a progressive, degenerative, terminal condition that affects more than 332,000 Australians. Although dementia is more common in older people, there are more than 24,700 Australians under the age of 65 who have dementia. Dementia causes a gradual change in cognitive function and affects people in different ways.

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

- Difficulties with memory
- Difficulties with everyday tasks, like handling money
- Difficulties with communication such as language or word finding
- Difficulties with perception

Most people with dementia live in the community. With support, many people with dementia are able to remain active and participate in many of the same activities they did before they received a diagnosis. There are some people diagnosed with dementia that may appear to have no external symptoms at all.

# 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, and will want to carry on using your business.

This information sheet will provide you with some very basic information that can help you to provide a better service to people 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 with dementia are over 65 but some are younger. A person with dementia may appear confused and disorientated or they may lack insight. Some may appear to have no external symptoms at all. There is no singular presentation as the disease exhibits across a range of domains.

Some people 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 that they are having problems that might be caused by dementia.

These may include:

- Looking or saying that they are confused or lost
- They might appear to be searching for something they can't find
- They might be looking like they don't know what to do next
- They might have problems handling their money or knowing how to use their credit card; they may also have registered to continue signing their credit card
- They might be finding self-service facilities hard to understand
- Their speech might be hard to understand or they may have difficulty finding the right words
- They might appear to have problems understanding what you are saying.
- They might forget to pay for things they've picked up

UNDERSTAND ALZHEIMER'S

**EDUCATE AUSTRALIA** 

FIGHTDEMENTIA.ORG.AU

There are of course a range of reasons why people might be having these problems that have nothing to do with dementia or memory problems.

# How can I communicate better with a person who has dementia?

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

People with dementia have told us that some of the key principles of good communication include:

- 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, not the 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 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

### 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 them in a friendly open manner, and ask "can I help?" It really is that simple, and for many people 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 selfservice 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 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 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 are 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 any one else involved that this may be a contributing factor.

# **Q:** What if none of this works 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, then call them. If none of this works, and the person appears to need help, then you should call your manager for help.

If you are the manager, or are working alone, then depending upon the nature of your business and location you could call emergency services or the police for assistance.

# Where can I get more information?

http://isitdementia.com.au/ provides a resource for staff working in retail, community services and emergency services that provides further information on how to respond to people who may have dementia.

If you want to find out more about dementia, please contact Alzheimer's Australia on 1800 100 500.

This resource as adapted from Innovations in Dementia (2012). Help – Pack for customer-facing staff.



# DEMENTIA LANGUAGE GUIDELINES

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

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

The words used to talk about dementia can have a significant impact on how people 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, and
- 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 with dementia is unique, as there are many different types of dementia and symptoms may present differently in different people.

# 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 with dementia to help people stay positively and meaningfully engaged, and retain feelings of self-worth.

For a full copy of this guide, including background information on the preferred terms listed in the table go to: www.dementiafriendly. org.au

You can find more information about dementia at: www.fightdementia.org.au

UNDERSTAND ALZHEIMER'S

**EDUCATE AUSTRALIA** 

FIGHTDEMENTIA.ORG.AU

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)
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About themselves) A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About someone else)	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 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	Person living with dementia



CONTEXT	PREFERRED TERMS	DO NOT USE
IMPACT OF CARING	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	Carer burden Burden of caring
PEOPLE WITH DEMENTIA UNDER 65	Younger onset dementia	Pre-senile dementia Early onset dementia
THE IMPACTS OF DEMENTIA	Disabling Challenging Life changing Stressful	Hopeless Unbearable Impossible Tragic Devastating Painful
SYMPTOMS OF DEMENTIA	Describe the symptom itself e.g. reduced vision, hallucinations, difficulty communicating Describe the impact it is having e.g. difficulty communicating	
BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTA	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



For more information:

www.fightdementia.org.au National Dementia Helpline: 1800 100 500

