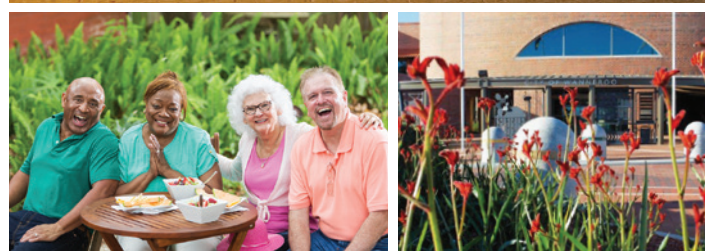


GUIDELINES FOR THE DEVELOPMENT OF DEMENTIA-FRIENDLY COMMUNITIES



A practical model for local
governments, civic services
and community organisations



alzheimer'swa
the dementia experts

ACKNOWLEDGEMENTS

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GUIDELINES FOR THE DEVELOPMENT OF DEMENTIA -FRIENDLY COMMUNITIES

A PRACTICAL MODEL FOR LOCAL GOVERNMENTS, CIVIC SERVICES AND COMMUNITY ORGANISATIONS.

FOREWORD – HON TONY SIMPSON MLA

Dementia remains one of the biggest national and international health challenges facing our generation. The number of Western Australians living with dementia is estimated at 32,000 and it is the second biggest cause of death for Australians.

The WA Government acknowledges the excellent work of researchers in seeking to find a medical solution - some of the top scientific minds from the State and around the world are working to find a cure.

Until we find that cure, we need to know how to address the needs of people with dementia living in our communities and how they perceive and experience the daily challenges they face during their journey.

In 2014, the WA Government provided funding to Alzheimer's Australian WA to deliver the Dementia-Friendly Communities project.

This project is an Australian first, designed to explore how to create dementia-friendly communities, which is described by Alzheimer's Australia as "a city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life".

The project has provided the opportunity for hundreds of people to tell us what it is like to live with dementia and the challenges they face in the community.

The information gathered has been used to create guidelines to facilitate change by assisting carers and community partners to understand how people living with dementia experience their world and to make the changes needed to ensure they can live well.

This project will provide the essential guidance needed to ensure Western Australia works towards a dementia friendly society by considering what strategies should be in place and where our energies need to be focused.

I commend Alzheimer's WA for their leadership in making this project a reality.

Yours sincerely,






HON TONY SIMPSON MLA

Minister for Local Government; Community Services;
Seniors and Volunteering; Youth

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	INVOLVING PEOPLE WITH DEMENTIA
	AWARENESS, UNDERSTANDING AND INCLUSION
	ENABLING ENVIRONMENT
	ASK, ANALYSE, ACT
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GLOSSARY OF TERMS

A

ACTIVITIES OF DAILY LIVING (ADL's):

The basic personal care tasks that must be performed to maintain some degree of independence, such as eating, transferring (e.g. moving from bed to chair), walking inside and outdoors, dressing, grooming, bathing and toileting.

AGE FRIENDLY: "Encourages active ageing by optimizing opportunities for health, participation and security in order to enhance quality of life as people age." Dr Alexandre Kalache, Director Ageing and Life Course Programme, WHO

ALZHEIMER'S DISEASE: A disability characterised by impaired memory and ability to learn new material, accompanied by a high level of stress and an acute sensitivity to the social and built environment.

ASSESSMENT: An evaluation of a person's condition or personal needs to enable them to live as independently as is possible. Assessment is a process that is ongoing and is vital to therapeutic care and support of people with dementia.

C

CARER: A family member or paid helper who regularly looks after a person living with dementia.

COGNITION: All the components of the mental process. These include awareness and comprehension of ideas, things, and events; retention of the experience; retrieval of it; sequencing ideas, forming concepts, and learning from them; reasoning and forming judgments and opinions.

C

CONSUMER: A client or family receiving services or support.

CUEING: The provision of prompts or hints, often verbal and/or visual to assist the person with dementia with orientation, to initiate or complete a task or stage of a task. Objective is to maintain independence of the person with dementia.

D

DISABILITY ACCESS AND INCLUSION PLAN (DAIP):

The purpose of DAIPs is to ensure that people with a disability can access all information, services and facilities provided by local governments in WA and be included in the community. (Government of Western Australia)

DEMENTIA: An umbrella term for a range of symptoms which manifest into a decline in intellectual functioning caused by a disease or other injury to the brain. The most common symptom involves loss of memory. From a psychosocial perspective, dementia is a disability characterised by impaired memory and ability to remember, learn new material, a high level of stress and sensitivity to the social and built environment.

D

DEMENTIA-FRIENDLY COMMUNITY (DFC):

A dementia-friendly community is a place where people with dementia are supported to continue living with meaning, purpose and value.

DYSPHASIA: Where the person has difficulty understanding what is being said.

E

ENABLING ENVIRONMENT:

A constructed environment that allows people living with dementia independence, opportunity and choice about their daily living needs.

EXECUTIVE FUNCTION: Ability to set a goal; make decisions and implement appropriate activities to meet those goals.

G

GAIT: Person's manner of walking. People with Parkinson's disease or Lewy Body dementia may have a "shuffling" gait while people with Alzheimer's disease have a reduced gait, because as they become more disabled they lose the ability to lift their feet.

L

LIVING WITH DEMENTIA: Can refer to not only the person living with a diagnosis of dementia, but their family and close friends involved in their care.

P

PERCEPTION: The conscious recognition and interpretation of external stimuli using any of the senses. Correct interpretation is based on unconscious association with memory and is the basis for correct understanding and learning of new information.

R

REMINISCENCE: An activity to promote a "sense of wellbeing" by getting in touch with long held memories and experiences and using these recollections to trigger and stimulate communication both verbal and non-verbal.

S

STIGMA: Social or psychological barriers that cause a person to feel shame or disgrace.

W

WAYFINDING: The ability to navigate to an intended place without difficulties and return from where you came.



INTRODUCTION

FOREWORD

DEMENTIA-FRIENDLY COMMUNITIES

Can you imagine a world that becomes so inaccessible that it prevents you from enjoying the simple pleasures of accessing places and services in your community that are available to everyone else? That is the reality for many people with dementia - the world is not designed to accommodate them.

In Australia, more than 353,000 live with dementia. Of those, we know approximately 70% live in the community – a community that is important to them and something they want to continue to be engaged with. I'm sure this would also be your preference if it were you.

Given this, and given Alzheimer's WA's long involvement in dementia enabling environments and design, we wanted to explore the concept of dementia friendly communities in the Australian context.

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, in part because they are able to continue to participate in the normal life of the local community.

With huge support from the WA government through the Social Innovations Grants Scheme and the Department of Local Government and Communities, Alzheimer's WA secured funding for a two year Dementia Friendly Communities (DFC) project. The DFC project sought to not only identify what contributed to a dementia friendly community in the Australian context, but also what was required to support businesses and community systems that wanted to make their communities dementia friendly.

The WA DFC project started in 2014 with research with more than 300 people around WA living with dementia to establish base line data and to inform the project. Since then there have been hundreds of hours of consultation, teaching, development, pilot projects and collaboration. One of the outcomes of the DFC project is this resource – the Guidelines for the Development of Dementia Friendly Communities. It is a practical model and useful tool for local governments, civic services and community organisations.

We have been overwhelmed by the support for this project, in particular many of WA's local governments, and to whom we say a special thanks.

This is the first guide of its kind in Australia. I thank the WA Government and the Department of Local Government and Communities for its commitment to fund and support of this project. I also thank and acknowledge Professor Richard Fleming and his team at the University of Wollongong who have made such a brilliant contribution.

I also acknowledge the efforts of our own DFC team who have strived tirelessly to ensure this project was evidence based on research undertaken with people living with dementia, and that it was person centred, practical and well as being accessible to all. The project was designed on a capacity building model with an ardent hope that it would leave information and resources on completion that would go on being useful in the months and years ahead. Given there was no framework or previous work in existence, the project achieved much as a first step, not the least is this guide.



Finally, I thank all of those living with dementia – those with a diagnosis and their carers – for their unselfish and courageous contribution to informing this work.

Every journey starts with a single step. We hope that you are considering your first step towards being a dementia friendly community. On behalf of my team, and the thousands of people living with dementia in the community, I congratulate you for your decision to become dementia friendly, and commend this resource to you and your team as you start this important work.

Best wishes

RHONDA PARKER

CEO Alzheimers WA

Dementia may affect us at any age, though its prevalence increases later in life. Dementia is the single greatest cause of disability in Australians aged over 65 years and the third leading cause of disability overall. In March 2015, the Australian Bureau of Statistics revealed that dementia had become the second leading cause of death in the nation, behind only heart disease¹.

As highlighted by the outcomes in the National Framework for Action on Dementia 2015-2019, Dementia-Friendly Communities need to be a major focus for Australia to enable increased awareness and reduction of risk to the 342,800² people currently living with a diagnosis of dementia. In 2013, Alzheimer's WA identified the need to explore the principles and definition of Dementia-Friendly within the Western Australian community and put it into a local context.

A successful application was put forward to the WA Department of Communities Social Innovations grant program to:

- 1. Address the stigma** many people with dementia face;
- 2. Respond to the needs and challenges** expressed by people living with dementia in their local community;

- 3. Provide sustainable outcomes** for both businesses and communities that meet the national framework for dementia in WA; and

- 4. Develop enabling environments** for people with dementia that will focus on public spaces and increasing accessibility in public buildings.

The intended outcomes of being able to support, foster and develop Dementia-Friendly Communities, together with the feedback from the thirteen WA pilot sites, are the key drivers that have encouraged the creation of this resource. Alzheimer's WA is focussed on a society committed to preventing dementia, while valuing and supporting people who live with dementia. Whilst there have been improvements in community awareness and understanding of dementia, there is still a long way to go and many people diagnosed with dementia still feel stigmatised and excluded from their communities.

¹ Alzheimer's Australia (September 2015) White Paper

² Australian Institute of Health and Welfare (2012) Dementia in Australia

The Government of Western Australia, through the Social Innovations Grant Program, funded this project to be future-focussed and to help WA work towards becoming Australia's first dementia-friendly state. The *Guidelines for the Development of Dementia Friendly Communities* is based on the experiences of people living with dementia in WA and the key priorities they described to the project. It provides tools, resources and ideas to commence a Dementia-Friendly project initiative. The views of people living with dementia count and understanding their experiences living in the community is the first step on the road to a truly Dementia-Friendly Western Australia.

The question at the centre of the consultation period for this project was **'How can we create dementia-friendly communities?'** A total of 13 community consultation workshops were conducted with people living with dementia, their carers, family and local government representatives. The workshops were completed in a range of metropolitan and regional locations across Western Australia.

The consultation explored three key areas: Positive experiences, frustrations and barriers, and what a dementia-friendly community would look like or include.

By engaging those living with dementia, their families, carers and local government representatives, an extensive understanding has been developed.

Eight key outcomes and suggested future actions for creating a dementia-friendly community were identified;

1. Reducing the stigma and improving community awareness and understanding;
2. Increasing the knowledge and understanding of dementia in health services;
3. Developing built environments to enable people with dementia;
4. Working with business and services to support customers with dementia;
5. Improving support and information for families and carers;
6. Improving access to social clubs and activities;
7. Increasing availability of person-centred care services; and
8. Improving transport support.

Creating a Dementia-Friendly Community is challenging. The study of the drivers of a Dementia-Friendly Community is a good first step. It represents one of the first attempts made to engage people living with dementia on their needs. While there is still work to be done to create a truly dementia-friendly WA, the findings influencing these guidelines have established aspirations for a positive future-focused approach³.

³ Alzheimer's WA (2015) Dementia Friendly Communities Project: Creating a Dementia Friendly WA. A report on the state-wide consultation on the experience of living with dementia in WA.

A dementia-friendly community is a place where people with dementia are supported to continue living with meaning, purpose and value.

Each dementia-friendly community will be different to the next, but will include at least one or more of the following:

- Businesses that provide accessible services for people with dementia, including staff who understand the condition and know how to communicate effectively with people with dementia.
- Organisations that support paid work or volunteering opportunities for people with dementia.
- Organisations that recognise the needs of carers in the workforce.
- Sporting clubs and social groups that are welcoming and inclusive.
- Adult education facilities that support new learning opportunities for people with dementia.
- Environments that are enabling and compensate for the disabilities of dementia.
- Opportunities for people living with dementia to have their views and experiences heard.

WHY DO WE NEED TO MAKE WA A DEMENTIA-FRIENDLY COMMUNITY?

Social stigma can have a devastating impact on the lives of people with dementia. Post-diagnosis not only brings cognitive changes, but also changes how family and friends respond to that person. Increased community awareness and understanding about dementia will support people to continue to be involved in activities they enjoy, reduce social isolation and add meaning, value and purpose to their day-to-day lives. Improving the physical environment, such as the use of appropriate signage, lighting and colours, will make it easier for people with dementia to remain engaged in their community.

It is estimated that over 65% of people diagnosed with dementia live at home and will continue to access their local communities. As the Australian population ages, we are seeing a much greater prevalence of dementia in Western Australia. It is estimated that by 2050, the number of people with dementia in WA will have more than doubled its current level to over 68,000 people. Because it is Western Australia's second leading cause of death, it is critical that we develop a dementia inclusive society that promotes risk reduction, provides timely diagnosis and supports people living with dementia to lead a high quality life in an inclusive community.



DEMENTIA IN WA

BENEFIT TO PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS

“A dementia-friendly community will recognise the need for a person with dementia to continue their lives and to participate in the community in activities they enjoy, whether through employment, volunteering or social activities.”

Kate Swaffer; person with dementia and Chair, Alzheimer’s Australia Dementia Advisory Committee.⁴

The onset and progression of dementia has considerable implications for the person’s daily life and engagement with society. As well as a decline in cognitive capabilities, people with dementia may also experience changes in their personality and emotional state that can negatively affect their opportunities for social interaction. In addition to changes, which are directly related to dementia, some people also experience a profound sense of social isolation and lack of purpose due to social stigma⁵. Dementia is a human condition, and without the development of a Dementia-Friendly Communities practical approach, the needs of those living with dementia and their families within our community will not be addressed.

⁴ Kate Swaffer presentation (April 2015), Alzheimer’s Disease International Conference, Perth, Australia.

⁵ Alzheimer’s Australia (September 2015) Dementia Friendly Communities White Paper

THE BENEFIT TO CIVIC SERVICES AND COMMUNITY ORGANISATIONS

Dementia is the greatest cause of disability for people over the age of 65⁶. With this information in mind, and coupled with the fact that we are also an ageing population, it then leads us to ask the question; how are we going to engage this demographic in our community and provide best practice service to meet their needs?

These guidelines contain the resources, direction, and living examples needed to commence Dementia-Friendly Communities work within a variety of community organisations and civic service structures. Contained within each chapter will also be a 'call to action' enabling you and your colleagues or staff to apply Dementia-Friendly principles to your work space.

These tools and living examples will support greater accessibility and inclusion for people caring for and living with dementia, inclusion in community activities increasing social connectedness, provision of improved services to all clients or customers including those with dementia, and increased return business as the service/ building will be appealing and appear deserving of the patronage of those living with dementia and older Australians.

By commencing Dementia-Friendly work, in conjunction with these guidelines, the workplace will take part in developmental learnings together to enable sustainability and longevity of the project.

These learnings will also empower individuals to establish the "why" of the change that is needed, and to identify key areas of development to each site.

BENEFITS TO LOCAL GOVERNMENTS STRATEGIC PLANNING

Local Governments play a vital role in the lives of people with a disability and seniors. Local governments are multi-functional, with extensive responsibilities and activities across property, community and human service areas and, in addition, have the capacity to make policy choices at a local level.

All of these local government functions and capabilities directly or indirectly have an impact upon the quality of life of the people who live, work and socialise in their local communities, including people living with dementia.

The opportunity for the inclusion of Dementia-Friendly planning and initiatives within local government policy readily presents itself as both Age-Friendly Planning (AFP) and Disability Access and Inclusion Plans (DAIP) can support Dementia-Friendly principles in key areas. By incorporating the elements Dementia-Friendly Community principles share with DAIP's Seven Outcomes and the Eight Age-Friendly Domains, inclusion can be incorporated into existing mandates, preventing the need to create new policy or frameworks.

⁶ Access Economics (2009) Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050.



ALZHEIMER'S WA DEMENTIA-FRIENDLY COMMUNITIES PROJECT

LIVING WITH DEMENTIA COMMUNITY CONSULTATIONS

Alzheimer's WA received a Social Innovation Grant from the Department of Local Government and Communities to implement the Dementia-Friendly Communities Project. To review the current situation and hear the voices of people living with dementia, Alzheimer's WA hosted community consultations and invited people living with dementia and their carers/support persons with the purpose of understanding what it is like to live with dementia in their community.

The series of workshops focused on how to create Dementia-Friendly Communities (DFC) and provided the opportunity for increasing awareness, advocacy and understanding of what it is like to live with dementia in Western Australia. The workshops also provided the forum for attendees to provide feedback, voice their opinions and help make a difference for people living with dementia in WA.

This initiative explored the experiences of people living with dementia, and based on the findings from the thirteen workshops carried out across the state of WA, community commonalities were identified and gave way to the development of the eight steering recommendations outlined in the report.

The findings from the consultations were centred on three key questions and recorded according to the **three core discussion topics: positive experiences, frustrations and barriers, and suggested changes.**

Suggested changes were mostly in relation to changing attitudes and awareness around dementia including education and training, as well as creating dementia friendly services and facilities.

The intention of the report was to communicate the lived experience of those who; are living with a diagnosis of dementia; care for someone with dementia; or, have been affected by dementia.

Through communicating these messages, it was the aim that the content would increase the conversation and action around the concept of Dementia-Friendly Communities, encourage the government to prioritise the implementation of dementia-friendly aspects in their strategic planning process, and contribute to the planning and policy-making of Alzheimer's WA.

The target audience for the report included the State Government (particularly the Department of Local Government and Communities), Local Government (particularly Community Development and Planning departments), consumers, workshop participants and service providers.

COMMUNITY CONSULTATIONS RECOMMENDATIONS

The report examined the findings from the workshop series in two ways; firstly, an overall perspective that covers all responses and identifies the key themes and opportunities.

COMMUNITY CONSULTATIONS RECOMMENDATIONS

Secondly, it reported findings based on the location of each workshop, providing links to the local government and service providers, thereby allowing a more targeted analysis of the experiences of those people living with/caring for someone with dementia in each location.

Listed on the following tables are the eight recommendations to have been derived from the consultation process.

Outcomes for a Dementia-Friendly WA	Consumer Recommendations	Recommended Action
Reducing stigma through improved awareness and understanding of dementia in the general community	<ul style="list-style-type: none"> Increased awareness in schools Greater awareness across the community of the impact of living with dementia Raised profile of dementia through utilising famous people and a campaign approach 	<ul style="list-style-type: none"> Establish a schools dementia awareness program across WA to inform and educate students Comprehensive WA community awareness campaign to de-stigmatise dementia and increase understanding Raise profile of Dementia Awareness Month (September) Recruitment of high profile dementia ambassadors to raise awareness
Increased knowledge of dementia in GPs hospitals and primary health services	<ul style="list-style-type: none"> Better awareness and support from GPs Easier and quicker diagnosis Increased dementia understanding and skills from allied health professionals Development of a consistent dementia-friendly hospital approach 	<ul style="list-style-type: none"> GP training program to aid early detection and referral to support services Improved accessibility to specialists to aid diagnosis Dementia specialist training programs to be available for allied health staff e.g. dentists, optometrists, podiatrists etc. Hospitals to adopt dementia enabling environment design Increased dementia training for hospital staff Family support packs available on hospital wards Adoption of dementia champions in each hospital

COMMUNITY CONSULTATIONS RECOMMENDATIONS

Outcomes for a Dementia-Friendly WA	Consumer Recommendations	Recommended Action
Development of built environments that enable people living with dementia	<ul style="list-style-type: none"> • Dementia design principles to be included in planning and development process • Improved dementia accessibility to public buildings e.g. shopping centres, library, museums etc. • Address urban design considerations for people living with dementia 	<ul style="list-style-type: none"> • Improved dementia appropriate signage to aid wayfinding • Incorporation of dementia design principles in design process • Inclusion of dementia specialist knowledge on planning and advisory groups • Review of existing accessibility of buildings for people with dementia • Consideration of the needs of people with dementia in local government urban planning
Increased awareness of customers needs with dementia in businesses and services	<ul style="list-style-type: none"> • Knowledgeable and aware business staff to recognise the needs of customers with dementia • Consumers to be able to identify dementia-friendly businesses and services 	<ul style="list-style-type: none"> • Incorporation of dementia specific training programs for service staff • Development of resources and support for businesses and services to become dementia-friendly • Development of a symbol for people living with dementia to recognise dementia-friendly businesses
Increased support and information for families/carers	<ul style="list-style-type: none"> • Improved access to training and information for families throughout WA • Development of a one stop shop for family support, information and education 	<ul style="list-style-type: none"> • Expansion of existing dementia specific training and information services • Improved marketing to help families become aware of what is available • Expansion of Alzheimer's WA information and resource centres • Family information packs to be available at pharmacies, medical surgeries etc.



Outcomes for a Dementia-Friendly WA	Consumer Recommendations	Recommended Action
Improved access to social clubs and activities for people living with dementia	<ul style="list-style-type: none"> • Broader services that enable the person and carer/family to socialise together • Existing groups and clubs to be inclusive of people living with dementia e.g. golf clubs, Men's Sheds, gyms etc. 	<ul style="list-style-type: none"> • Dementia training and information programs for community social clubs • Dementia inclusion planning by local governments • Support to museums, galleries etc. to develop dementia specific services and accessibility
Increased availability of person-centred care services	<ul style="list-style-type: none"> • Increased access to dementia specialist day and overnight respite services • Equality and consistency in the provision of person centred dementia care in residential facilities 	<ul style="list-style-type: none"> • Expansion of innovative flexible dementia specific respite service options • Development of local community cottage respite in rural communities • Increased training for aged and health care staff on person-centred care • Recognition of need for younger onset dementia specific services
Improved transport support for people with dementia	<ul style="list-style-type: none"> • Access to training for staff to recognise the needs of passengers with dementia • Better awareness of current and available services for people living with dementia • Improved facilities/ modes of transport for people living with dementia e.g. frequency and flexibility of services across WA 	<ul style="list-style-type: none"> • Dementia awareness and understanding training to be available for public transport and taxi staff • Public transport design to be dementia-friendly and accessible • Transport wayfinding and information to be supportive of people with dementia • Regional needs for public transport services to be considered • Recognition of disabled parking needs for people with cognitive impairment

Alzheimer's WA (2015) Dementia Friendly Communities Project: Creating a Dementia Friendly WA. A report on the state-wide consultation on the experience of living with dementia in WA.

ALIGNMENT OF AGE FRIENDLY AND DAIP

Several areas are distinctly paralleled when embarking on becoming Dementia-Friendly to that of becoming Age Friendly and the development of Disability Access and Inclusion Plans.

Dementia is the leading cause of disability for people over the age of 65, and a key focus of becoming dementia-friendly is incorporating equal opportunities for those living with dementia and their families into business plans, into the community and into support and health services. Considering the impact dementia has on an individual and their family, including dementia as a part of a revised Disability Access and Inclusion Plan is an opportunity to incorporate the needs of a significant group into this planning. While reviewing Disability Access and Inclusion Plans consultations take part within the surrounding community. If people living with dementia are included in these consultations, the information can be integrated easily into the planning process and fit into the development component of the revised DAIP.

According to The World Health Organisation (WHO) the term “Health” refers to “a complete state of physical, mental and social well being, and not merely the absence of disease or infirmity⁷”. Age Friendly communities have been established on this principle and the same drivers are behind that of the Dementia-Friendly Communities movement. Although the Age Friendly movement abides by eight domains, the domains are fluid and conjoined with one another to enable users to fit the principles into current policy and planning frameworks. It is for this reason that the development of dementia-friendly communities presents itself as a ready-made tool to merge into existing age friendly work. Care must be taken at this point to not exclude those living with younger onset dementia (defined as people living with dementia under the age of 65 years of age), and to make sure the needs of this group are also heard and addressed in access and inclusion planning.

⁷ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

ASK, ANALYSE, ACT



- Consider how you could include the specific needs of people with dementia in your DAIP or Aged Friendly plan
- Use the tools in this guide to incorporate consultations and outcomes for people living with dementia into your planning
- Review your DAIP and/or Aged Friendly Plan and ask how relevant it is for people living with dementia
- Utilise the Alzheimer's WA Dementia-Friendly Communities Audit and Planning Guide to start the process of analysing how dementia-friendly your organisation is



CHAPTER 1

INVOLVING PEOPLE LIVING WITH DEMENTIA

FOREWORD

LISTENING AND RESPONDING TO CONSUMERS

Listening and responding to consumers - that is, people living with dementia, and their carers - is a vital part of “getting it right” when it comes to creating dementia-friendly communities.

Given the somewhat alarming projection of about 900,000 Australians diagnosed with dementia by 2050 or around 7,400 new cases each week, and given that many will choose to remain living at home in their community for as long possible, it is crucial that adjustments are made at home and in the broader physical and social environments for the well being of those living with dementia and their carers.

Alzheimer’s WA is an organization that is genuinely consumer-driven. Together with my wife, Dr Glenda Parkin, who was diagnosed with younger onset dementia more than five years ago, we have been active participants as consumer advocates for Alzheimer’s WA, at both state and national levels.

Consumers are realists: They speak from the lived experience with dementia and their voice gives important insights into planning for their future care and management. Their contributions and reactions to ideas and suggestions have helped shape the content of this chapter.

To involve people with dementia in issues and matters that directly affect them may seem initially challenging, but experience over several years has demonstrated otherwise. In fact, Australia and Western Australia are among the world’s leading countries and local jurisdictions in dementia care and management – in part, because of the participation of people living with dementia in consultations and on committees and working groups.

Glenda and I, like other people living with dementia, want simple outcomes from all this work. We want to live our lives in the same community as everyone else and we would love to see growth in the understanding of the unique challenges that people living with dementia face.

BRONTE PARKIN

Educator and Public Speaker

Carer for Partner Living with Dementia

Dementia Advocate

Director, Alzheimer’s WA Ltd



INVOLVING PEOPLE LIVING WITH DEMENTIA

The voices of people with dementia and their carers are at the start and the heart of the process of creating dementia-friendly communities. Dementia-friendly communities are responsive to what people want, but perhaps more importantly, people with dementia have the right to have a sense of ownership, investment, responsibility and connectedness to their own communities⁸.

Throughout this chapter, we will be exploring the ways in which people living with dementia can be involved in a broad range of processes and advocacy within the community. Using inspirational examples listed from WA, Australia and around the world, the aim is to recognise the importance and relevance of connecting with this demographic, and presenting opportunities to those individuals to shape how communities respond and support them in their daily lives.

Being able to specify a way of life in which to live is a basic human right. Unfortunately, this is often not the case nor the norm for people living with dementia. An all too familiar approach is to discount the person with dementia's ability to contribute, instead taking on professional opinions and carer's point of view as what the person living with dementia desires. Due to the increases in timely diagnosis, there has been a corresponding increase in the number of people living with dementia who are very capable of self-advocating and sharing their experiences. This shift has led to a rise of people living with dementia who want to shape and have input into planning their own support and care.

In this chapter consider how, in varied forms, you could empower someone living with dementia by involving them in the decision making that could shape their future.

A movement gaining fast momentum around the world that provides opportunity for the voice of people living with dementia to be heard is that of dementia alliances.

⁸ Innovations in Dementia: Dementia friendly communities- Guidance for councils DEMENTIA ALLIANCES



CHAPTER 1

INVOLVING PEOPLE LIVING WITH DEMENTIA

DEMENTIA ALLIANCES

"A Dementia Alliance is made up of people in the community who are interested in helping to make their community or town more dementia friendly.

It must include people with dementia, alongside others such as carers and family members of people with dementia, local councils, business owners, community groups, schools and just about anyone who is interested. A Dementia Alliance will look different in every community depending on who is involved and the aims of the group⁹".

ASK, ANALYSE, ACT



- View information on how to set up a Dementia Alliance group in the below link or look to the resources section of this guide:

act.fightdementia.org.au/sites/default/files/Community_toolkitpdf

Linking in with dementia organisations, local service providers and seniors groups can provide a start point for forming a dementia alliance and recruiting people living with dementia to join.

⁹ Creating Dementia Friendly Communities- Community Toolkit Alzheimer's Australia 2014

ADVOCACY - HEARING THE VOICE OF PEOPLE LIVING WITH DEMENTIA

WESTERN AUSTRALIA

In Western Australia, Alzheimer's WA acts as a conduit for people living with dementia to actively promote their choices in lifestyle and care. Alzheimer's WA values the engagement, involvement and consultation of people living with dementia and encourages them to share their story about dementia.

This enables:


- The voice of the consumer to be heard.
- Raised awareness of dementia and its impact on families.
- Increased community understanding about living with dementia.
- Reduced the stigma associated with dementia in our society.
- The ability to help government and service providers recognise the needs of people living with dementia, their carers and families.



The Dementia Advocates Program aims to ensure WA hears the voice of people living with dementia (e.g. people with a diagnosis and/or their carers) and amplifies this to the wider community, whether that be on a national or international level. The program also strengthens consumer participation in the work AAWA undertakes in awareness raising, research, policy and service delivery.

ASK, ANALYSE, ACT



- To find out how you can involve Alzheimer's WA's advocates in your dementia-friendly activities please contact:
Consumer Engagement Coordinator
(8) 9388 2800 or email: dfc@alzheimerswa.org.au 

AUSTRALIA

The National Australian Consumer Advisory Committee provides advice, guidance and consumer representation to Alzheimer's Australia regarding issues of importance or concern to consumers. The National Consumer Advisory Committee was formed in 2005 as a result of the Alzheimer's Australia 2005 National Consumer Summit. The feedback and contribution of members helps to inform policy and advocacy work, submissions, funding applications, publications, consultations and awareness raising campaigns¹⁰.

THE WORLD

Dementia Alliance International is a non-profit group of people with dementia from all around the world that seek to represent, support, and educate others living with the condition. It is an organisation that will provide a unified voice of strength, advocacy and support in the fight for individual autonomy and improved quality of life. It provides online support groups, blogs and webinars, and a range of resources for people with diagnosis and their carers. Membership is open and exclusive to anyone with a diagnosis of any type of dementia across the world¹¹.

¹⁰ <https://fightdementia.org.au/national/about-us/consumer-groups/national-consumer-advisory-committee>

¹¹ <http://www.dementiaallianceinternational.org/>



CONSULTATION

Consulting with people living with dementia is a positive first step toward becoming dementia-friendly, highlighting the strengths and areas for opportunity within the community or business profile. As mentioned in the previous chapter, the Dementia-Friendly Community WA project embarked on a state wide consultation to shape the outcomes of these Guidelines. The community consultation process that is required to investigate the age-friendly features and barriers in a community, closely mirrors that which you would commence in taking the first steps to become Dementia-Friendly. The same applies for the community consultation process that is required to review a Disability Access and Inclusion Strategic Plan.

The Alzheimer's WA Dementia-Friendly Community's Project: Creating a Dementia-Friendly WA Report has demonstrated that, given the right support, individuals with dementia are willing to express opinions, views and preferences about their communities in which they live. However, professionals often require assistance with identifying and using opportunities for meaningful consultation.

Researcher Kate Allen has stated that "identifying starting points for consultation requires careful consideration of the person's strengths and needs regarding communication, their background and interests, and apparent feelings about the topic. Resources such as pictures, word cards and objects prove helpful for stimulating conversation and interaction for some people. These need to be carefully chosen, again with the person's background and current interests in mind. Providing opportunities for people to talk about topics in an indirect way, for example, speculating on what another person's opinions might be, usually works better than asking people direct questions¹²".

¹² Kate Allan JRF (2003) *Exploring ways for staff to consult people with dementia about services*

ASK, ANALYSE, ACT



- The Dementia-Friendly Communities WA Report in full can be located in the resource section of this guide.



ASK, ANALYSE, ACT



- Are people living with dementia represented on your access and inclusion panel?
- Contact Alzheimer's WA's Dementia Advocates Program and ask a Dementia Advocate to participate and provide feedback in your group, activity or consultation.
- Develop your own local Dementia Alliance. See the resource page of this guide (Community Toolkit: local dementia alliance).
- Start your own local government dementia reference group and ask participation of a Dementia Advocate in this group.
- Run a community consultation for people living with dementia in your region.
- Utilise the Dementia-Friendly Communities consultation process Involving People with Dementia, in the Resources section of this kit.
- View the Steve Milton lecture on Dementia-Friendly Communities at: www.youtube.com/watch?v=sFf5B1tTUo8



RESOURCES

Alzheimer's Australia - Dementia Language Guidelines

fightdementia.org.au/sites/default/files/full-language-guidelines.pdf

Alzheimer's Australia Creating Dementia-friendly Communities: Community Toolkit: Starting a Local Dementia Alliance.

act.fightdementia.org.au/sites/default/files/Community_toolkit.pdf



CHAPTER 1

INVOLVING PEOPLE LIVING WITH DEMENTIA

OTHER WAYS TO ENGAGE PEOPLE LIVING WITH DEMENTIA

WALKTHROUGHS

A walkthrough, as the title suggests, is walking through a space or location with someone who is living with dementia.

According to Hampshire County Council¹³, this can be a very effective way of finding out more about how people with dementia experience their local environment. Arranging to go with them to visit these places can provide some really valuable insights into how they experience their environment.

It can also help to identify ways in which local facilities can be supported to become more dementia-friendly. One might assume that this activity is only suitable for people in the early stages of dementia. Certainly, people in the early stages may need less support, and may be more active in their communities. However, it is wrong to assume that people with more advanced dementia cannot enjoy the process and contribute equally valuable insights.

¹³ Hampshire County Council (2012) *Making Hampshire a dementia-friendly county: Toolkit for engaging people with dementia and carers*

ASK, ANALYSE, ACT



- When designing or refurbishing a venue, invite a person with dementia and their support person to walk through the venue with you.
- Visit the Dementia Enabling Environments Website: www.enablingenvironments.com.au
- Watch people with dementia talking about their experiences: www.youtube.com/watch?v=z15-0xZTng4



VOLUNTEER PROGRAMS

Alzheimer's WA conducted a pilot project that found **meaningful engagement through volunteering helped the person with dementia to feel valued** and included as part of an organisation and that they were still able to make a meaningful contribution to society. This in turn increased their overall self-esteem and quality of life.

Alzheimer's WA believes in focussing on the person with the diagnosis rather than just the disease. This follows the belief that people with dementia are still able to contribute to society in meaningful ways and one way of doing this is by participating in a volunteering program.

People with a recent diagnosis of dementia often feel a loss of meaning and purpose in their lives due to the changes associated with their dementia. Whilst some people may feel they are no longer able to contribute, this is rarely the case.

Through the volunteer program, a person with early dementia is given the opportunity to use their talents and abilities to continue to contribute to society.

By participating in the volunteering program, people with dementia also help to break stigmas and raise awareness within the wider community about dementia and the abilities a person can still retain¹⁴.

¹⁴ Alzheimer's WA "Volunteering Program Report" 2011

MEMORY CAFÉS

Memory Cafés (also called Alzheimer's cafés) are social gatherings where people experiencing memory loss and their carer/support person come together to **connect and support one another in a relaxed, non-judgmental atmosphere**.

Some cafés include engaging activities and provide additional information and support based on the needs of their community. Refreshments and entertainment are common elements and gatherings can take place in locations such as community centres, museums and existing cafés.

Fifteen years ago, Memory Cafés emerged in Holland and have thrived across Europe because these grassroots community-building programs are low-cost, early interventions that complement more traditional support services for people with dementia and their carer/support person. The memory café movement is gaining momentum in the US, with at least 60 new cafés now in operation.

In Australia, the Australian and Victorian governments, under the Home and Community Care Program, have provided funding for Café Style Support Programs that are offered throughout Victoria.

vic.fightdementia.org.au/vic/support-and-services/services-and-programs/memory-lane-caf%C3%A9



ONLINE MEMORY CAFÉS

Café Le Brain is an online Memory Café facilitated through Dementia Alliance International. The cafés are accessible in the USA, Canada, UK, Australia, New Zealand and most regions in Asia. All people living with dementia and their supporters are welcome to attend. Café Le Brain use video conferencing to bring people together for conversation, learning, support and fun.

www.dementiaallianceinternational.org/events/cafe-le-brain/

ASK, ANALYSE, ACT



- Consider running a drop in Memory Café in your community.
- Ensure people living with dementia are aware of online groups such as Dementia Alliance International.



RESOURCES

Memory Café:

Toolkit for Building a Neighbourhood Memory Café (Carole Larkin, Third Age Services)

thirdageservices.com/MemoryCafe.html

Alzheimer's Café Handbook by Jytte Lokvig

thirdageservices.com/AlzCafe%20handbook.pdf

A Guide to Setting up a Memory Café (David Light and Jim Delves, Devon, UK)

www.repod.org.uk/downloads/REPoD-mc-guide.pdf

Example Programs:

Corwall Memory Café Network Video

www.youtube.com/watch?v=edLP2XUHf5A

Arthur's Memory Café, Roseville, MN, US

www.jarthursmemorycafe.com/about/

CASE STUDIES

INVOLVING PEOPLE LIVING WITH DEMENTIA



WORKING TOWARDS A DEMENTIA-FRIENDLY KIAMA

Alzheimer's Australia is working in collaboration with people living with dementia in Kiama.

Kiama Municipal Council and the University of Wollongong created a dementia-friendly community in Kiama. At the heart of this is the recognition that people living with dementia want to participate in everyday activities, and are able to do so with support and community understanding. Just like any other Australian, people with dementia want to have meaning and purpose in their lives. Alzheimer's Australia, the University of Wollongong and Kiama Council are committed to test a range of innovative initiatives to address social inclusion, physical design and community understanding of dementia in the local area.

There are five key areas to creating a dementia-friendly Kiama.

These are:

- 1. Listening to people with dementia** about what is important to assist them to live well with dementia the Kiama community.
- 2. Establishing a Local Dementia Alliance** that will work towards making Kiama dementia-friendly. Members of the alliance will include people with dementia, local government, community organisations, businesses and schools, which includes people with dementia.

The alliance will meet regularly to support, discuss, provide advice and promote the initiative in the local community.
- 3. Supporting local organisations and businesses** to become dementia-friendly through making small changes that will have large impacts on the lives of people with dementia. A recognition process will be developed for organisations and businesses that commit to improving their services and practices to make them more accessible to people with dementia. This process will be supported through training and resources developed by Alzheimer's Australia.
- 4. Raising awareness of dementia** through providing information sessions, public lectures and education opportunities for all members of the community.
- 5. Working with organisations** to promote volunteering, employment and other social engagement opportunities for people with dementia. The partnership approach is an essential part of achieving social change in Kiama.



CASE STUDIES

INVOLVING PEOPLE LIVING WITH DEMENTIA



Dementia-friendly is everybody's business and each organisation plays an important part in achieving the goal of a dementia-friendly community in Kiama. The local grassroots knowledge and ownership is provided through Kiama Council. The national leadership to translate the dementia-friendly concept to a locally relevant strategy is provided by Alzheimer's Australia. The importance of collecting social research data through the initiative to demonstrate evidence of the effect of the initiatives is critical. Each partner organisation is committed to improving the lives of people with dementia in the community and sharing the lessons from this work with other communities.

This initiative presents huge opportunities not only for the Kiama community but for all Australian communities as the prevalence of dementia increases.

In 2050, there is predicted to be over 900,000 Australians living with dementia. All Australians with dementia should have the opportunity to be directly involved in the dementia-friendly initiatives and a chance to live in an accepting and inclusive community that supports, understands and encourages people to live well with dementia¹.

¹ First Steps to a Dementia Friendly Australia, 2014
Alzheimer's Australia Inc.

**THIS INITIATIVE PRESENTS
HUGE OPPORTUNITIES
NOT ONLY FOR THE KIAMA
COMMUNITY BUT FOR ALL
AUSTRALIAN COMMUNITIES
AS THE PREVALENCE OF
DEMENTIA INCREASES.**



ALBANY PUBLIC LIBRARY AND HAWTHORNE HOUSE- WORKING TOGETHER TO MAKE ALBANY DEMENTIA FRIENDLY

In early 2015, Albany Public Library made a commitment to start the process of becoming dementia friendly.

Situated in the South of WA, the library is an existing service provider to the Town of Albany and its surrounds. The library team, led by Paul Nielsen, had a large task at hand and decided to form a working group (made up of library staff, Alzheimer's WA Community Inclusion Officer, members and staff from a local day respite centre Hawthorn House, and a local member of the local government). Albany library now had a reference point for any ideas they wanted to action. The decision to embark on this journey was celebrated by hosting a morning tea at the library, supported by the local government. Members of the public were invited along with members living with dementia from Hawthorn House, health providers, carers and local government bodies. A small presentation was given and people living with dementia in Albany were being included in conversations around stigma, awareness and education and how the library could play an instrumental part in these.

Education of frontline staff was quickly identified as a starting point and an Alzheimer's WA Albany Education Officer ran sessions for the staff and volunteers.

An internal service review followed to identify what current services were classed as dementia-friendly and what areas there were for improvement. A physical audit of the building also took place. The building audit was completed by both the library and members and staff of Hawthorn House, this allowed for the information gathered to be impartial and honest. Once the data was collected, the working group reconvened and discussed the options that could be actioned. A detailed action plan was drawn up by the library to include the addressed items and to ensure they were actioned in a timely manner. The agenda included items such as signage, review of flyers, development of inclusive book groups and addition of further dementia books to the library collection.

As a direct result of this library taking part in piloting a dementia-friendly approach, they have now established a firm relationship with Hawthorn House, its staff and members. Activities that are ongoing include; members have expressed their interest in volunteering at the library, an option that is being looked into, the library staff are looking at making regular visits to Hawthorn House to increase and maintain their levels of awareness and understanding of dementia, members are frequently consulted by the library on action plan items and both parties contact each other outside of the pilot program's jurisdiction.



CHAPTER 2

AWARENESS, UNDERSTANDING AND INCLUSION

FOREWORD

COLLABORATIVE PARTNERSHIPS

The Western Australian Museum's mission is to inspire people to explore and share their identity, culture, environment and sense of place, and to experience and contribute to the diversity and creativity of our world.

Underpinning this are the Museum's core values of which the first two are particularly relevant to this publication. They state that the Museum will be:

- **Accountable:** *We exist for the benefit of all the people of Western Australia and recognise that we are accountable to them and are custodians of their collections.*
- **Inspirational, Inclusive and Accessible:** *We will inspire people to explore our world and will advance knowledge through study, research and life-long learning; making sure that our facilities, programs and resources are accessible to all.*

Through its policy and practice, the Western Australian Museum is committed to ensuring that all aspects of the Museum are fully accessible to all sectors of the community by removing or reducing any physical, sensory or intellectual barriers to access.

The Museum interprets fully accessible to mean that all Museum activities, facilities and services (both in-house and contracted) are open, available and usable to people with disabilities, providing them with the same opportunities, rights and responsibilities enjoyed by other people in the community.

Since committing to its first Disability Access and Inclusion Plan, in 2007, the Western Australian Museum has implemented a number of improvements. Those challenges experienced by people living with dementia, were at the centre of our thinking when looking to increase accessibility to our many facilities and services.

The Museum collaborated with Alzheimer's WA as part of its commitment to achieving this increased accessibility.

Twelve months into this collaboration, the Western Australian Museum is becoming a dementia-friendly organisation, more aware, better trained and with much-improved understanding of the issues involved.

There have been two particular highlights which have seen the WA Museum chart a course towards true dementia accessibility.



The first of these was offering our first 'dementia friendly' tours, with specially trained guides, which have provided new insights, both for visitors, and the Museum. They are transforming our service and our thinking, and are opening doors to families living with dementia.

The second highlight was hosting the *Great Men by Great Boys* and *Great Women by Great Girls* exhibitions as part of our contribution to Dementia Awareness Month. This presented the living histories of a number of Western Australians, some of whom had dementia, that illustrated both their contributions to, and their frustrations with, a society that often tried to embrace them, but did not always understand them and their needs.

It has been both salutary and rewarding to explore how the WA Museum can develop its resources and support framework for current and potential visitors in the community who are either, experiencing, or caring for those who are facing the challenges of dementia.

One of the main benefits is the opportunity to 'upskill' our own team, so that they may consider the ways in which even small changes in approach to planning programs, events and experiences might make a significant difference to the participation of, and contribution by, those experiencing dementia.

The relationship with Alzheimer's WA, and opportunity to draw on the expertise of their staff, and through representatives of the dementia community in WA, has been invaluable. Whilst we may be at the early stages of this dialogue, I look forward to how we can explore and seize future opportunities.

As museum workers, you would expect us to experience a strong sense of history: in doing so, we recognise the role that people with dementia have played, and continue to play, in our society.

Recognising this, and acting upon it, not only improves our own performance as a transformational organisation, but enriches the experiences of both our users and our staff.

ALEC COLES OBE

Chief Executive Officer

Western Australian Museum



CHAPTER 2

AWARENESS, UNDERSTANDING AND INCLUSION

Raising awareness and understanding of dementia is central to developing a dementia friendly community.

The more the general public understands dementia, the stronger the interest and support will be. Raising awareness can bring the term 'dementia' out in the open and help people living with dementia be better understood and valued. It can also encourage people to explore opportunities to reduce the risk of developing dementia. Raising awareness may mean that a person living with dementia can continue to make a substantial contribution to their community.

A crucial first step to achieve this is to reduce dementia stigma. People with dementia want to be accepted for who they are, not defined by their diagnosis.

Dementia awareness is a basic understanding about what dementia is, how it affects those living with the condition and how to effectively interact and support a person living with dementia and their family.

The aim of 'Awareness Understanding & Inclusion' is to increase the community understanding and awareness of dementia, reduce the stigma associated with dementia and inspire change in the attitude towards people with dementia to create communities that positively support people living with dementia and their families.

Due to the acknowledgment of Australia's ageing population and the increase in dementia research and care, the disease has a higher profile in the community. The publicity may have increased, however, much of the associated discussion regarding dementia has focused on the negative and most debilitating aspects of the disease. Therefore, although public awareness is increasing, the information being portrayed in some instances increases the negativity and can have the potential of increasing public fear and a social stigma.



Misconceptions of dementia not only have a profound effect on the general community, but also on the person living with dementia and their family. Stigma prevents people from acknowledging symptoms and obtaining help which, in turn, affects the process of early diagnosis as well as referral to services and support¹⁵.

The purpose of this section is to raise public awareness about the effects of stigma associated with dementia, to address the way society approaches dementia and to eliminate public misconceptions of the disease. By recognising the retained abilities of a person living with dementia and their capacity to participate in the community, we are ensuring the feelings of being active, engaged and valued.

Alzheimer's WA believes more awareness and understanding of the disease and of the personal perspective would reduce negative connotations, lead to social empathy, reduce fear and therefore reduce stigma.

¹⁵ *Overcoming the Stigma of Dementia*, 2012, World Alzheimer Report, Alzheimer's Disease International(ADI) London.

EDUCATION

Dementia awareness training programs can improve staff knowledge and confidence in assisting people living with dementia.

With a relatively minor investment in staff education, there is a noticeable improvement in staff attitudes and practices regarding the assistance and support of people living with dementia.

Effective public education provides positive, simple messages about dementia and corrects misinformation and misconceptions.

ASK, ANALYSE, ACT



Dementia education training programs for staff are an effective way of improving knowledge and awareness about dementia and building staff confidence in assisting those living with a form of dementia.



EDUCATION

Unfortunately, stigma around dementia remains all too prevalent. Many people continue to believe that the individual with dementia has no insight into their condition and cannot adequately express their own needs and desires. There is also a great deal of fear and shame around dementia¹⁶. In her innovative project, Helen¹⁶ spreads the message that people living with dementia are competent, valuable human beings and we must create a space in which their potential can be fully realised.

It has been noted in several discussion papers and with the Alzheimer's WA Dementia Advocates that dementia awareness and understanding needs to include a wide audience and be appropriate for young people as much as in the older age groups.

In compiling the research findings of the Dementia-Friendly Communities project report education, awareness and understanding were noted across all sectors of the community as key issues. Targeting young people in the community was consistent as a suggested area for action.

Education and training was also recommended by people living with dementia for a broad range of professionals that interacted with people living with dementia, particularly retail businesses, the service industry and health professionals.

It should be noted that if businesses work towards becoming dementia-friendly, it would improve the reputation and patronage of the business. Using the corporate education program run by Alzheimer's WA the organisation can provide appropriate awareness and education to all staff. This can include information on how dementia affects people, customer service skills - including offering communication, reassurance, patience and understanding.

¹⁶ I will tell you something of my own, Helen Gregory, The Journal of Dementia Care, March/

ASK, ANALYSE, ACT



- Plan staff training in dementia awareness.
- Promote the Alzheimer's WA Dementia-Friendly Communities education packages to local business and agencies especially front counter staff. Go to: www.alzheimerswa.org.au/our-services/education/
- Ensure that the appropriate language guidelines developed by Alzheimer's Australia are used in your publications and material.
- View the "Is It Dementia." Resource: isitdementia.com.au

April 2014, vol22 no 2.



“Unhelpful attitudes usually occur when people are ignorant of what is happening; wide public information is needed.”

– Carer¹⁸

“Stigma can significantly negate a person’s dignity and self-reliance.”

Carers and people living with dementia believe negative attitudes and discrimination from the community can be reduced if community awareness and education was increased across all age groups of the community.

STIGMA:

Stigma is defined as ‘mark of disgrace associated with a particular circumstance, quality or person¹⁷’. It defines the person who is the recipient of the stigma and sets them apart as an undesirable, rejected stereotype (rather than in an accepted, normal one).

To alleviate the discrimination and misconceptions surrounding dementia, a greater awareness and understanding of dementia and the lived experience of people living with dementia is required.

Increasing awareness of dementia is a crucial component to dispel the misconceptions that build and maintain stigma associated with the disease; such as the myth that memory loss is a normal part of aging or that people living with dementia can no longer be an active member of society.

The perceived stigma attached to dementia needs to be challenged.

Increased community awareness and understanding of dementia is needed to inform the community that all people living with dementia are individuals who should expect to be respected, cared for and supported. People living with dementia should maintain their dignity and be considered as people who can give something and not people who are helpless. They should not be identified because dementia has become a part of their lives but because of their continuing place in the world.

¹⁷ *Concise Oxford Dictionary 12th ed.* Oxford: Oxford University Press 2011, p 1418.

¹⁸ *Addressing the Stigma Associated with Dementia*, Discussion Paper 2. Alzheimer’s Australia NSW, Sept 2010.



CHAPTER 2

AWARENESS, UNDERSTANDING AND INCLUSION

"I always say to people who are looking after us, try and just be present with us, because by being present, you can truly connect with us, just by eye contact or touch."

Just let us know that you are there with us, not negating our feelings or in some way patronising us, but that you are on an equal level with us and that you are also truly present."

– Christine Bryden



RESOURCES:

Before I Forget: How I Survived a Diagnosis of Younger-Onset Dementia. Christine Bryden, Penguin Books Australia, 2015, ISBN 9780670078745.a

Diagnosed with dementia at 46, Christine Bryden has been a passionate advocate for people living with dementia all over the world, working to break down stigma and stereotypes about dementia for the past 20 years.

ASK, ANALYSE, ACT



- Educate staff on appropriate language to use when referring to dementia and when assisting people living with dementia and their families.
- Discuss with your team their image of a person with dementia and talk openly about dementia in positive terms and what a people living with dementia individual abilities are and not what they cannot do. Do not refer to a people living with dementia in a negative light i.e. as helpless or a sufferer.
- Read the World Alzheimer's Report 2012 *Overcoming the Stigma of Dementia*: Chapter 3, located in the resource section of this guide.



RAISING AWARENESS

Dementia Awareness Month (DAM) is held in Australia in September each year. The goal is to encourage Australians to become dementia aware, have a better understanding of what it is like for a person to live with dementia, and ultimately, be encouraged to create communities where people with dementia are supported to live a high quality of life with meaning, purpose and value. This innovative promotion is an opportunity for organisations to get out into the community and promote dementia awareness and education to the community.

Dementia Aware Friends (DAF) project is an initiative in which volunteers are trained to spread the message to friends, family and members of their community about dementia, how it affects people's lives and how they can make a positive difference to people living with dementia in their community. The DAF project is part of the Dementia-Friendly Communities project.

ASK, ANALYSE, ACT



- Request a DAM kit from Alzheimer's WA to display at your workplace.
- Promote dementia awareness through display of posters or information.
- Invite the Dementia Aware Friends team to participate in community events, exhibits and shows within the local community setting.



LANGUAGE

Language is very powerful.

There is positive and negative language and the way it is used can change our mood, our attitude and the way we perceive our environment.

When considering the subject of dementia negative terms that stereotype the characteristics of a people living with dementia are all too familiar. As are the jokes to try to make light of the condition. To persist in using terms like “dementia sufferer” and “demented” will ensure that dementia, and by association the person, is always thought of in a negative light.

Language shapes the beliefs, identities and behaviours around dementia.

The images that negative language create are difficult to eradicate but can be relieved by promoting positive language and accurate information about the nature of the condition. The stereotyped idea of a person with dementia as someone who is by definition confused and helpless, unable to communicate, let alone hold a rational conversation or contribute their own ideas to a discussion is very upsetting for many people living with dementia¹⁹.

This misconception can result in less interaction and an eroding of the relationship of the people living with dementia and family members and friends and further increase social isolation.

It is important to use language that focuses on abilities of the people living with dementia to help people stay positive and meaningfully engaged, and retain feelings of self-worth.

Negative language, especially in the media, is often used to describe Alzheimer’s disease and other dementias. The wording tends to focus on the illness and reduces people with the disease to a series of labels, symptoms or medical terms.

Spreading the word about positive language can help reduce the stigma surrounding dementia (particularly in the media).

¹⁹ Overcoming the Stigma of Dementia, 2012, World Alzheimer Report, Alzheimer’s Disease International(ADI) London



ASK, ANALYSE, ACT



- **Use and encourage positive language such as:**
 - Always using the person's own name when referring to an individual.
 - A person or people **living** with dementia.
 - A person living with dementia is **affected by** dementia.
 - As **experienced** by people living with dementia.
- **Communicating with people living with dementia and their families by:**
 - Include the people living with dementia in the conversation by using their name, do not talk over the people living with dementia as if they are not present.
 - Sometimes changing wording in the conversation and speaking clearly can make a big difference in people living with dementia understanding and being able to participate.
- Watch the presentation on language by a person with dementia:
www.youtube.com/watch?v=TaHDKCWzMog
- Ensure the language guidelines available from Alzheimer's WA are available to all staff and part of staff development training.



RESOURCES:

A "call to action" launched by DEEP and Dementia Action Alliance (DAA)

www.dementiaaction.org.uk

dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

www.fightdementia.org.au/resources/dementia-language-guidelines



CASE STUDIES

AWARENESS, UNDERSTANDING AND INCLUSION



ART GALLERY OF WA

The Art Gallery of Western Australia is home to two engaging programs for people living with dementia.

On board from the beginning, the gallery realised the non-pharmacological benefits to hosting community based art programs for people living with dementia. The Gallery guides receive compulsory annual training from Alzheimer's WA and dementia specific programs can be found on their website.

During 2009, Alzheimer's WA created a new arts program "*Moments with McCubbin*" funded by the Australian Government through the 'Dementia Community Grants Program'.

The program was designed for different groups of people living with dementia, these groups included; residential care, day centre clients and couples living at home where one partner was living with dementia.

The program consisted of four guided art tours (one of which was a touch tour of a sculpture) and a final art session in the gallery studio, an experience usually offered to school students.

The feedback was overwhelmingly positive across all the groups, with the Art Gallery of WA wanting to continue with a new guided tours program "*Art and Memories*".

Alzheimer's WA focussed on creating "*Artistic Adventures*" **a specific program for couples living at home in the community who have limited opportunities to access an intellectually stimulating creative program.**

Developed with educators and guides from the gallery, this project aims to encourage creative expression and social inclusion through monthly guided tours of the gallery and hands-on sessions in the gallery's studio. Here everyone becomes an artist, and enjoys working with various mediums to create individual works of art. Following the tour and art sessions, the group meets at the gallery café for refreshments and great conversation. The programs are now in their seventh successful year and have a waitlist of over 20 couples wanting to take part.



HIBISCUS SHOPPING CENTRE (NT)

‘Stepping Out’ is a social activity-based group for people living with memory loss. The group is supported by Alzheimer’s Australia NT to participate in social outings, group discussions and activities within the community.

For many years, the Alzheimer’s Australia NT ‘Stepping Out’ group has visited the Hibiscus Shopping Centre as part of the program. Hibiscus is a small northern suburbs shopping centre providing services to many local families and older Territorians. **The businesses in the centre often come together to provide a free morning tea for the ‘Stepping Out’ group.** Strawberry Fields, the central café in the centre, hosts the get together with all members of the community enjoying the event. Building relationships and connecting to people and their stories is what life in the territory is all about. Without these relationships, meetings can be just words. Alzheimer’s Australia NT and the Thursday ‘Stepping Out’ group have grown their relationship with Hibiscus Shopping Centre to one that will not only benefit themselves but also benefit the entire community.

The ‘Stepping Out’ group has become part of the Hibiscus Shopping Centre family. The centre manager has experienced first-hand the challenges of patrons who have cognitive impairment and with that has come **a yearning to provide them with the best possible experience they can have during their visit to the centre; to feel safe and included.**

Alzheimer’s Australia’s NT staff have met with the centre manager on many occasions during the morning teas and discussions have now taken a new direction. There is much talk about dementia and what makes a dementia friendly environment. The centre manager, Laura, with the support of other key businesses has set a goal to take steps towards being the first dementia-friendly environment in the territory.

Achieving this goal would also mean the centre would be creating a pathway towards reducing stigma and discrimination and would be working towards the full inclusion of people living with dementia. The key steps towards reaching this goal will include staff education and awareness raising throughout the centre. The ‘Stepping Out’ group supports the key personnel to walk in their shoes and look at signage, lighting, noise levels and resting places through the centre, while also conducting an environmental audit as they go. Planning towards a new dementia-friendly tomorrow is well and truly underway.

As they work towards creating a dementia-friendly shopping centre, the staff and businesses at Hibiscus Shopping Centre would help to provide an opportunity for regular conversations about dementia, **help change community attitudes and support acceptance for those people living with dementia.**

What an achievement this would be².

² First Steps to a Dementia Friendly Australia, 2014 Alzheimer’s Australia Inc.



CHAPTER 3

ENABLING ENVIRONMENTS

DESIGNING PUBLIC SPACE FOR PEOPLE LIVING WITH DEMENTIA

FOREWORD

HOW TO DESIGN ENVIRONMENTS

Our understanding of how to design environments that support people with dementia in their pursuit of independence and pleasure has increased steadily since the early 1980s.

Just as importantly the awareness and acceptance of this knowledge has also increased, so much so that the demand for the application of this knowledge is much stronger than it used to be.

While in the 80s the focus of designing for people with dementia was confined to specialist residential facilities, these days there is an increasing awareness that the knowledge has application in other areas. Happily it is becoming quite common for the planning of hospital refurbishments and new acute care facilities to include a careful consideration of the needs of people with dementia. **But perhaps the most exciting development is the growing expectation that the knowledge can be applied in the all-encompassing field of the development of dementia-friendly communities.**

While we must be cautious about our ability to do this, as there is very little empirical work to guide us, it is time for us to take up the challenge of making our local shops, banks, supermarkets, doctors' surgeries, council offices, etc. capable of supporting people with dementia as they go about their everyday life. The DEEP website has set the international standard for putting the available knowledge on designing environments for people with dementia into an easily accessible format, freely available to all who need it. The addition of information and tools on applying this knowledge to the development of dementia friendly communities is clearly the next step.

PROFESSOR RICHARD FLEMING

Director, NSW/ACT Dementia Training Study Centre
University of Wollongong
Australia



One of the key components of a dementia inclusive society is maintaining opportunity to continue to access the community and its services.

Often barriers to this can exist created by poor physical environmental design.

With very limited guidance on dementia specific design in Australian Accessibility Standards or Universal Design guidelines, this area is often neglected by architects and urban designers when creating public access buildings and spaces. Over 70% of people with dementia continue to live in their own home and will access public buildings and local community spaces.

The Dementia Enabling Environment Project (DEEP) provides a range of resources, information and tools to assist in creating dementia enabling environments. Using 10 evidence-based principles of dementia design as guidance, environments can enable the person with dementia to continue to lead a full and active life with reduced impact of cognitive impairment.

The 10 dementia design principles are:

1. Unobtrusively reduce risks

People with dementia require an internal and external environment that is safe, secure and easy to move around in order to support their wellbeing. Safety features and barriers need to be as minimal as needed and be sympathetic to the rights and expectations of an adult. Unobtrusively incorporating safety features to minimise risk whilst allowing quality of life and not being blatantly obvious are achievable goals.

2. Provide a human scale

The scale of a building will have an effect on the behaviour and feelings of a person with dementia. The experience of scale is determined by three factors; the number of people that the person encounters; the overall size of the building; and the size of the individual components, such as doors, rooms and corridors. A person should not be intimidated by the size of the surroundings or confronted with a multitude of interactions and choices. Instead, the scale should help the person feel in control.

3. Allow people to see and be seen

The provision of an easily understood environment will help to minimise disorientation. It is particularly important for people with dementia to be able to recognise where they are, where they have come from and what they will find if they head in a certain direction. When they can see destination points, they are more able to make choices and find their way to where they want to go. Buildings that provide these opportunities are said to have good visual access. Good visual access opens up opportunities for engagement and gives the person with dementia the confidence to explore their environment.



4. Reduce unhelpful stimulation

Because dementia often reduces the ability to filter stimulation and attend to only those things that are important, a person with dementia may become stressed by prolonged exposure to large amounts of stimulation. The environment should be designed to minimise exposure to stimuli that are not helpful. The full range of senses must be considered. Too much visual stimulation is as stressful as too much auditory stimulation. When reading signs too much visual “clutter” around the sign can distract from seeing the intended information.

5. Optimise helpful stimulation

Enabling the person with dementia to see, hear and smell things that give them cues about where they are and what they can do can help to minimise their confusion and uncertainty. Consideration needs to be given to providing redundant cueing, ie. providing a number of cues to the same thing, recognising that what is meaningful to one person will not necessarily be meaningful to another. A person may recognise a familiar shop, for example, because of the shop front, the presence of furniture, the colour of the walls, or the materials used in the carpet. Cues need to be carefully designed and placed so that they do not create unhelpful stimulation.

6. Support movement and engagement

Purposeful and safe walking can be supported by providing a well defined pathway, free of obstacles and complex decision points that guides people to their destination. Clear signage to aid orientation as well as land mark features to assist wayfinding are beneficial.

7. Create a familiar space

The person with dementia is more able to use and enjoy spaces and objects that were familiar to them in their earlier life. The environment should afford them the opportunity to maintain their abilities through the use of familiar building design (internal and external), furniture, fittings and colours. Use of familiar tap ware or furniture can help the person with dementia understand the purpose of the object and assist in its usage.

8. Provide opportunities to be alone or with others

People with dementia need to be able to choose to be on their own or spend time with others. This requires the provision of a variety of spaces, some for quiet conversation with one or two others and some for larger groups, as well as spaces where people can be by themselves. Creating mixed public spaces, some social, some private gives the person a choice depending on their needs.



9. Provide links to the community

Without constant reminders of who they were, a person with dementia will lose their sense of identity. Frequent interaction with friends, relative, neighbours and their community can help to maintain that identity. Considerate urban design that encourages community interaction and provides opportunities for neighbours to socialise can benefit people with dementia greatly. Many people with dementia state that they often feel isolated and lonely, disconnected from friends and their community.

10. Respond to a vision for way of life

The environment should support the person with dementia to lead a life that has meaning and value to them. Independence is something we all value and having a physical environment that supports independence and allows the person with dementia to maximise their abilities whilst minimising the impact of their impairments is crucial. Well designed community spaces and public buildings will encourage the person with dementia to continue to go to the shops, attend the community group, visit the cinema or walk the dog. Supporting lifestyle choices through good design is an achievable goal for the design and urban planning team.

- 1 Fleming R, Bowles J. Units for the confused and disturbed elderly: Development, Design, Programming and Evaluation. Australian Journal on Ageing. 1987 November;6(4):25-8.
- 2 Fleming R, Forbes I, Bennett K. Adapting the ward for people with dementia. Sydney: NSW Department of Health; 2003.
- 3 Fleming, R. & Bennett, K. 2013. Environments that enhance dementia care: issues and challenges. In: Nay, R., Garratt, S. & Fetherstonhaugh, D. (eds.) Older People: issues and innovations in care. Chatswood: Elsevier Australia.



CASE STUDIES

DESIGNING PUBLIC SPACE FOR PEOPLE LIVING WITH DEMENTIA

IMPROVING ORIENTATION AND WAYFINDING

One of the easy areas of change that can have a significant benefit is in the development of improved wayfinding and orientation signage (**Principle 6: Support Movement and Engagement**).

Good dementia enabling signage should be clear, have good contrast, be easily visible, lead a person on a pathway to the destination and not be surrounded with other information, whilst being easily recognisable symbol and word/s and preferably be on the door it relates to. Signage should also lead a person back from the destination if appropriate.

A person living with dementia described one of the challenges she has at her local shopping mall:

"I can find the toilet ok, but when I come out it is very confusing and I never know which corridor to take to get back to the shops. Sometimes I end up in the store room!"

Good dementia signage does not cost more but requires understanding of the needs of someone with dementia and how cognitive impairment effects wayfinding.



CASE STUDY:

Photo 1

Common public toilet signage that is reflective and provides poor contrast for someone with perception difficulties.

Photo 2

Readily available public toilet sign that is clear with good contrast.

Clear signage with good contrast, use of words and symbols and leading one from decision point to the next supports positive wayfinding for people with dementia.





ENHANCING ACCESSIBILITY

Dementia can cause spatial perception difficulties.

This is a common cognitive impairment for someone with dementia and is the way we interpret the space, objects and surfaces around us. It allows us to make sense of the objects in the space and how we can interact with it. People with dementia often have difficulty with spatial perception and patterns, shadows, colour contrasts etc can affect the interpretation of the object or space.

A common issue for people living with dementia is flooring patterns and materials in public buildings.

Floor patterns can significantly impact a person living with dementia in the way they see the floor surface and then how they respond (**Principle 4: Reduce Unhelpful Stimulation**).

Choosing floor surfaces/coverings that have minimal colour crossovers, not square tile colour contrasting, minimal bold patterning, low glare and non slippery surfaces will assist a person living with dementia.



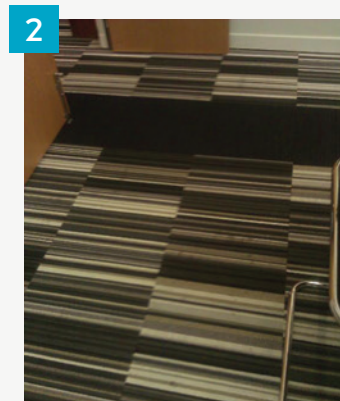
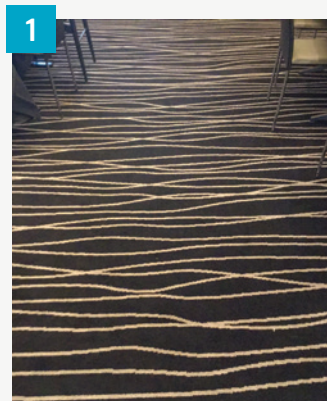
CASE STUDY:

Photo 1

Patterned carpet in hotel that would create difficulties.

Photo 2

Carpet design creates illusion of steps or holes.



This principle can also be applied to other floor surface areas such as steps, escalators and lifts. Choosing materials that reduce the colour contrast but still achieve the desired outcome is possible with careful consideration. Australian standards require raised tactile floor surfaces to assist visually impaired people. If these are done in a solid dark colour, it can create the perception of a large hole for someone with dementia. Using a sensitive design tile can avoid this.



The opportunity to maximise abilities for people with dementia can often rely on longer term memories or familiarity of an object or space (**Principle 7: Create a Familiar Space**). The push for aesthetic modern design and minimalism can often have a negative outcome for people with dementia who may be relying on longer term memories.

Wife talking about her husband's difficulties at his local restaurant:
"We have local, great food! Problem is in the toilets, the sink has no taps. You wave your hands around under it and sometimes water, sometimes soap, sometimes nothing comes out! He has great difficulty understanding it."

Using cross head taps, paper towels or obvious hand dryers and other fixtures and fittings with obvious purpose can support independence and enablement.

A series of illustrations on the DEEP website provide advice and ideas for dementia friendly design in public buildings. These areas include building frontage, reception, toilets and meeting rooms.

For further design information please visit the DEEP website:
www.enablingenvironments.com.au



CASE STUDY:

Photo 1 - Dark tiles create illusion of a hole.

Photo 2 - Dementia enabling design maintains function but does not impair a person with dementia.

Strong colour contrast on the floor can create difficulties for people with dementia with spatial perception problems. In this example, tactile floor surfaces in photo 1 could appear as a hole in the ground blocking the way for someone with dementia. Photo 2 shows the same outcome of tactile sensor needs for someone with visual impairment but with less impediment to people with dementia.





ASK, ANALYSE, ACT



- Visit the DEEP website and review the design information available.
- Conduct an audit of your environments using the Dementia Friendly Community-EAT audit tool.
- Ensure you have someone with a knowledge of the needs of people with dementia or a person living with dementia on your community accessibility review group.
- Incorporate dementia design principles into your aged friendly and disability inclusion and access planning.
- Book an Alzheimer's WA dementia design training session for your staff or planning team.



RESOURCES:

Dementia enabling environment website:

www.enablingenvironments.com.au

Dementia Friendly Community-EAT audit tool:

www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/alzheimers_enviro_assess_tool_a4-signoff.pdf

Garden audit tool:

www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/dementia_therapeutic_garden_audit_tool_2013.pdf

Gardens that care:

www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/gardens_that_care.planning_outdoor_environments_for_people_with_dementia.pdf

Adapting the Home:

www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/adapting_your_home_resource_book.pdf

Assistive technology helpsheets:

www.alzheimerswa.org.au/about-dementia/helpsheets/#toc



CASE STUDY

DESIGNING PUBLIC SPACE FOR PEOPLE LIVING WITH DEMENTIA



CITY OF MELVILLE ACCESS ADVISORY GROUP

The City of Melville formed the Access Advisory Panel to provide people with disabilities and mobility impairments with input into the planning approvals process.

It advises on how to improve upon minimum accessibility standards for large scale development applications, plans for special events, certain city initiated projects or programs and proposals for works on city-managed property.

The group recognised they did not have representation from someone with a knowledge of access issues for people living with dementia. Alzheimer's WA's Dementia Enabling Environment team were invited to have a representative on the group. This has led to ensuring the needs of people living with dementia are considered in building projects in the City of Melville as well as an opportunity to share knowledge with the rest of the group on dementia design considerations.

CHAPTER 1

RESOURCE LISTING



INVOLVING PEOPLE LIVING WITH DEMENTIA

- **Talk to Me Brochure:**
wa.fightdementia.org.au/research-and-publications/papers-and-evaluations/talk-to-me
- **Communication Help Sheet:**
wa.fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone01-Communication_english.pdf
- **Hampshire (UK) Toolkit for engaging people with dementia and carers:**
www3.hants.gov.uk/2012-dementia-friendly-communities-toolkit-engagement.pdf
- **What Works Resource Pack- Involving People With Dementia and making it count (UK):**
dementiapartnerships.com/wp-content/uploads/sites/2/what-works-resource-pack.pdf
- **How to Form a Dementia Alliance:**
act.fightdementia.org.au/sites/default/files/Community_toolkit.pdf
- **Steve Milton lecture on Dementia Friendly Community:**
www.youtube.com/watch?v=sFf5B1tTUo8
- **Toolkit for Building a Neighbourhood Memory Café (Carole Larkin, Third Age Services):**
thirdageservices.com/MemoryCafe.html
- **Alzheimer's Café Handbook by Jytte Lokvig:**
api.ning.com/files/*JoV1omPzSOgstAp3tXfw-ym8K1HV2sBNz7jBs*bbt4X9UH0lpmWbiuWBQMuevMZ-Fqea3Y11sJ3gdchMmDkM64iyi1EktU5/AlzCafehandbook.pdf



INVOLVING PEOPLE LIVING WITH DEMENTIA

- **Developing Dementia Inclusive Public Initiatives:**

www.artgallery.wa.gov.au/events_programs/documents/Art-and-memories-dementia-tours-2010.pdf

nga.gov.au/ArtDementia/

www.moma.org/calendar/events/60?locale=en

www.ifla.org/files/assets/hq/publications/professional-report/104.pdf

www.alz.org/nyc/in_my_community_17047.asp

- **Watch people with dementia talking about their experiences:**

www.youtube.com/watch?v=z15-0xZTng4

- **Community Consultation - How to run a consultation café session with people living with dementia:**

wa.fightdementia.org.au/guide-to-running-a-community-consultation-cafe

- **Age-friendly Communities a Western Australian Approach (the WA Age-friendly Toolkit):**

www.dlhc.wa.gov.au/Publications/Pages/Age-FriendlyWA-Toolkit.aspx

- **Disability Access and Inclusion Plans Resource Manual for Local Government:**

www.disability.wa.gov.au/Global/Publications/Understanding%20disability/Built%20environment/daip_manual-localat_govt.pdf

CHAPTER 2

RESOURCE LISTING



AWARENESS, UNDERSTANDING AND INCLUSION

- **World Alzheimer's Report 2012: overcoming the stigma of dementia:**
www.alz.org/documents_custom/world_report_2012_final.pdf
- **Addressing the Stigma Associated with Dementia; Discussion paper 2. Sept 2010 Alzheimer's Australia NSW:**
nsw.fightdementia.org.au/sites/default/files/2010NSWAddressingStigmaDiscussionPaper2.pdf
- **Exploring Dementia and Stigma Beliefs a Pilot Study of Australian Adults Aged 40 TO 65 Years:**
fightdementia.org.au/sites/default/files/20120712_US_28_Stigma_Report.pdf
- ***Is It Dementia* DVD Resource:**
isitdementia.com.au
- **A "Call to Action" Launched By DEEP And Dementia Action Alliance (DAA):**
www.dementiaaction.org.uk
- dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf
- **Alzheimer's WA Education and Training Courses:**
www.alzheimerswa.org.au/training
- **Language Guidelines:**
fightdementia.org.au/sites/default/files/full-language-guidelines.pdf
- **Presentation on language by a person with dementia:**
www.youtube.com/watch?v=TaHDKCWzMog



CHAPTER 3

RESOURCE LISTING

ENABLING ENVIRONMENTS DESIGNING PUBLIC SPACE FOR PEOPLE LIVING WITH DEMENTIA

- **Enabling Environments Website:**
www.enablingenvironments.com.au
- **Way-finding:**
www.enablingenvironments.com.au/orientation-and-way-finding.html
- **Use of Colour and Contrast:**
www.enablingenvironments.com.au/colour-perception-and-contrast.html
- **Public Building Audit tool and Spreadsheet:**
www.enablingenvironments.com.au/audit-tools-services.html
- **Adapting the Home:**
www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/adapting_your_home_resource_book.pdf
- **Gardens that care:**
www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/gardens_that_care_planning_outdoor_environments_for_people_with_dementia.pdf
- **Garden audit tool:**
www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/dementia_therapeutic_garden_audit_tool_2013.pdf
- **Assistive technology help sheets:**
www.alzheimerswa.org.au/about-dementia/helpsheets/#toc



- **Dementia Friendly Communities WA 2015 Report:**
www.alzheimerswa.org.au/who-we-are/dementia-friendly-communities
- **Living With Dementia in the Community 2014 National Survey:**
fightdementia.org.au/sites/default/files/DementiaFriendlySurvey_Final_web.pdf
- **State and National Facts and Statistics on Dementia:**
fightdementia.org.au/sites/default/files/20100326-WA-AccessReportMar2010-Rpt-v1.pdf
fightdementia.org.au/sites/default/files/NATIONAL/documents/Key-facts-and-statistics.pdf
- **National Framework for Action on Dementia 2015 – 2019:**
www.dss.gov.au/sites/default/files/documents/09_2015/national-framework-for-action-on-dementia-2015-2019.pdf
- **Dementia Friendly Community Guidelines Booklet**
www.alzheimerswa.org.au/about-dementia/being-dementia-friendly
- **Alzheimer’s Australia *Dementia Friendly Communities White Paper* (September 2015):**
wa.fightdementia.org.au/sites/default/files/NATIONAL/documents/Dementia-Friendly-Communities-white-paper.pdf
- **Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*:**
wa.fightdementia.org.au/sites/default/files/20111014_Nat_Access_DemAcrossAust.pdf
- **Innovations in Dementia (UK):**
www.innovationsindementia.org.uk



KEY REFERENCES:

Before I Forget: How I Survived a Diagnosis of Younger-Onset Dementia.

Christine Bryden, Penguin Books Australia, 2015, ISBN 9780670078745.a

I will tell you something of my own. Helen Gregory, The Journal of Dementia Care, March/April 2014 vol22 no 2

Concise Oxford Dictionary 12th ed. Oxford: Oxford University Press, 2011 p 1418

APPENDIX 1

ALZHEIMER'S WA DEMENTIA FRIENDLY COMMUNITIES AUDIT AND PLANNING TOOL



This document has been created as a guiding resource to initiate the process of becoming Dementia Friendly and bring awareness to Dementia Friendly Community concepts in your Local Government. It is the hope that by using this assessment tool, you will be able to identify key areas requiring development through physical adaptation, education and training or capacity building.

Date:	
Name:	
Position:	
Department:	



AWARENESS AND SOCIAL INCLUSION	Yes	No	N/A
1. Do you /your staff have knowledge of the different types and symptoms of dementia? <ul style="list-style-type: none"> ○ No understanding ○ Moderate understanding ○ High understanding ○ Mixed understanding (some knowledge but unsure of its accuracy) 			
2. Do you train staff in specific needs of people with dementia during staff training days? <ul style="list-style-type: none"> ○ Would dementia training better equip your staff? ○ Would the management team be open to staff training on dementia? 			
3. Are you including people living with dementia (e.g. someone with a diagnosis and/or their carer) in staff training to provide their lived experience?			
4. Are you or your staff aware of Dementia Awareness Month (September)? <ul style="list-style-type: none"> ○ Would you consider organising dementia awareness activities and events to increase community knowledge and understanding of dementia ○ Would you consider inviting people living with dementia to share their experience? ○ Are you in a position to create displays within facilities/ community to raise awareness about dementia? 			
5. Would your team be open to receiving feedback from people living with dementia in regards to you being Dementia Friendly?			
6. Would you consider regularly consulting people living with dementia on public, volunteer and commercial services on how to best serve them?			
7. Would you be interested in having a staff representative to be recognised as a Dementia specialist in your team?			

Identified actions:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____



PHYSICAL ACCESS	Yes	No	N/A
1. Are you or your staff aware of how dementia can effect a person's ability to move and function? <input type="radio"/> Would you benefit from an education session on dementia design?			
2. What environmental changes would your team have the capacity to implement? a. Signage : <input type="radio"/> Signs with large graphics and symbols in clear colour contrast to background <input type="radio"/> Signs have non-glare lighting and non-reflective coverings <input type="radio"/> Signage is fixed to walls at eye level and give clear and essential information only b. Furniture placement: <input type="radio"/> Furniture and furnishings should be contrasted against walls for easy visibility. <input type="radio"/> Furniture has rounded edges to reduce bumps and grazes c. Lighting: <input type="radio"/> Adequate and evenly distributed street lighting to assist those with dementia and lower visual acuity <input type="radio"/> Indirect lighting for good illumination level with reduced glare <input type="radio"/> No areas of deep shadow or glaring light d. Noise Levels: <input type="radio"/> Background noise is minimal with acoustic barriers such as grass rather than hard surfaces, trees, hedges and fencing in place <input type="radio"/> Sound absorbing materials, for example, acoustic ceiling tiles, wall hangings, upholstery and curtain fabrics used where possible e. Flooring: <input type="radio"/> Well maintained, plain, smooth, level, non-slip, non-reflective floor coverings <input type="radio"/> Flooring in clear colour contrast and material to walls and furnishings <input type="radio"/> Changes in texture or colour of floor coverings to indicate potential hazards <input type="radio"/> Level changes are clearly marked and well lit with handrails and non-slip, non-glare surfaces f. Other: <input type="radio"/> Simple lay-out with non-uniform, short, direct routes <input type="radio"/> Uninterrupted visual access to all areas, ideally with unobstructed views of at least 6 to 30 metres in both directions in buildings and other indoor areas <input type="radio"/> Where complete visual access is not possible, distinctive way-finding cues positioned at point where visual access ends. For example: potted plants, ornaments, paintings <input type="radio"/> Colour contrast toilet seats with toilet bowls and floor and uniform signage for male and female toilets			
3. Do you feel confident in assessing your facility in regards to dementia design? <input type="radio"/> Are you or your team aware of the Alzheimer's Australia DEEP website? <input type="radio"/> Have you used a dementia design audit tool?			



Identified Actions:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____



SOCIAL ENGAGEMENT	Yes	No	N/A
1. What areas of interest are relevant to your facility? <ul style="list-style-type: none"> ○ Group activities ○ Social Support ○ Community and Local interest/ engagement ○ Physical activities ○ Intergenerational programs ○ Annual events ○ Repeat attendance 			
2. Does your team currently run community outreach programs? <ul style="list-style-type: none"> ○ Are they inclusive of people living with dementia e.g. do they consider the specific needs people with dementia might have? ○ Would an education topic on this be useful for staff/ the facility? 			
3. Does your team have a volunteer program? <ul style="list-style-type: none"> ○ Do you have people living with dementia as a part of your volunteer task force? ○ Would your volunteers benefit from dementia training? ○ Would your site be interested in more information on the Alzheimer's Australia WA volunteering program? ○ Would your site be interested in taking part in the Alzheimer's Australia WA volunteering program? 			
4. Are sporting/social clubs and community organisations/facilities aware of the needs of people with dementia and are services tailored to meet those needs?			
5. Are community events and activities held so they can be attended alone or with a carer?			
6. Would your team have the capacity to run dementia specific programs/ activities, such as Memory Café's?			
7. Are flexible and appropriately paid opportunities for people with dementia to continue working, or become employed promoted?			
8. Are decision making bodies in public, private and voluntary sectors encouraging and facilitating membership of people with dementia?			

Identified actions:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____



ACTION AREAS

	Priority Area	Action to be taken	By who	By when
Awareness and Social Inclusion	1.			
	2.			
	3.			
	4.			
	5.			
	6.			



	Priority Area	Action to be taken	By who	By when
Physical access	1.			
	2.			
	3.			
	4.			
	5.			
	6.			



	Priority Area	Action to be taken	By who	By when
Social Engagement	1.			
	2.			
	3.			
	4.			
	5.			
	6.			

Thank you for taking the first steps to becoming dementia friendly



Government of **Western Australia**
Department for **Communities**

alzheimer'swa

APPENDIX 2

A Guide to Running Dementia Community Consultation Cafés

Introduction

Alzheimer's WA strives to improve the lives of people living with dementia and their families. As the peak dementia organisation providing leadership in care, advocacy, and education to the public and the health and aged care industry. We offer a holistic approach in our care that respects the individuality of people living with dementia.

In WA, there are more than 33,000 people living with dementia. Without a medical breakthrough, this number is projected to increase to over 38, 000 in under ten years. The majority of people with dementia live at home and are supported by family, friends and neighbours.

A key component of a Dementia Friendly Communities initiative is consulting with people living with dementia. This crucial first step to finding out exactly what is needed. Engaging this demographic in your community should be a part of the initial scoping of a dementia friendly community plan.

This guide will enable you to successfully undertake a ***consultation café*** in your community, allowing the voice of people living with dementia to be not only heard but understood.

Reasons for hosting a consultation café may include but are not limited to;

- The commencement of Dementia Friendly work
- Revision of a Disability Access and Inclusion Plan (on a state, local and community level)
- Age Friendly Projects- developing Age Friendly planning
- Planning and review of services to your community/ business provides
- Access and Inclusion panels for local government
- Development of new premises and civic sites

The Development of Community Cafés

Alzheimer's WA understands the effects that dementia has on the individual, family, friends and the broader community. It is important that those living with dementia or caring for someone with dementia are supported and a degree of sensitivity is maintained. For these reasons, the concept of the Community Café was developed. The philosophy of the workshop series was to create a relaxed, informal atmosphere where people with dementia would feel comfortable sharing their experiences. We provided a non-threatening environment for exploration and personal sharing by creating a format where participants are invited to a morning tea that allows socialising and sharing of experiences as well as consultation. When developing a consultation that is inclusive of people living with dementia there are several considerations that need to be taken into account:

- Time of day: mid-morning is often the best time for people with dementia as the ability to focus is at its best.
- Location of the venue: the venue needs to be easy to access by public transport and by car and have easy parking options.
- Interior design of the venue: carpeting, toilet facilities, acoustics, lighting should meet dementia design standards. Signage and way finding in and around the venue to improve accessibility.
- Language used in consultation: the language used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community. Appropriate terminology and sensitive language must be used.
- Formulation of questions: simple, short questions asking about one topic at a time.
- Distribute easy to understand agendas and timetable of events before meetings.
- Meeting duration should be limited to a maximum of 90 minutes, with a limited number agenda points/discussion topics.
- Slow down the pace of discussion to give people time to say what they want to say.
- Refreshments are essential. They help to relax, provide a break and give participants an opportunity to network and share.

The factors listed above will not only influence attendance, but the success of the consultation work taking place. You will be influencing all things within your control to achieve a successful event by ensuring your event has easy access (both via car and or public transport), inclusive legible marketing and is on a convenient day at an appropriate time of day,. What follows are some useful resources that can be found online to enable you to assess whether a venue is suitable.

Enabling Environments Website:
www.enablingenvironment.com.au

Public Building Audit tool and Spreadsheet:
www.enablingenvironments.com.au/audit-tools--services.html

Way-finding:

www.enablingenvironments.com.au/orientation-and-way-finding.html

Discussion Questions

When involving people living with dementia in discussion and feedback in a community café, it is vital to be clear about what you want to achieve from the consultation. This will help to guide you towards keeping the questions simple, open ended and supportive. Awareness needs to be given to ensure the questions are not prescriptive as you want to allow for discussion and creativity. Using examples to illustrate a point or question can work in the cafés to allow flow of thought and to ensure that everyone is on task. Alzheimer's WA utilised the following questions and examples when completing their Community Cafés for the Dementia Friendly Communities (DFC) Project;

The DFC Community Café series was centred on three key questions:

1. In regards to living with dementia in your community, what has been a positive experience for you and your family?
2. In regards to living with dementia in your community, what has been a frustration or barrier for you and your family?
3. If you could make changes in your community, what would a dementia-friendly community look like or include?

Each question had approximately 10-15 mins discussion time and tables shared their discussions at the end of each question. Large A1 pieces of paper were at the centre of each table of 4-6 people with marker pens to record the discussion points as they arose.

An example was given for each of the three discussion questions. This was done in an effort to ensure the question was understood while adding a personal touch and providing the opportunity for participants to relate better to the facilitators.

The examples given for question 1 (positive experiences) and question 2 (barriers and frustrations) remained the same for every workshop. The examples regarding a dementia-friendly community were different for each workshop, and specific to the area within which the workshop was held. This was to encourage participants to think in their local context when generating possible changes needed to make their community dementia-friendly.

Promotion of the Event

Attracting people living with dementia to attend the event is a critical component of a successful outcome. Marketing with attractive, easy to read material that appeals to the target audience is essential. The material should provide not just factual information about the event but also be a call to action and explain the purpose of the consultation. We have included an example of the poster used for the Alzheimer's Australia WA Community Cafés outlining the importance to balance visual appeal with space in order for it to remain

legible? Partnering with your local Alzheimer's Australia organisation provides a useful avenue to increase marketing appeal and gain interest in your event. Contact details for your local organisation can be found at fightdementia.org.au.

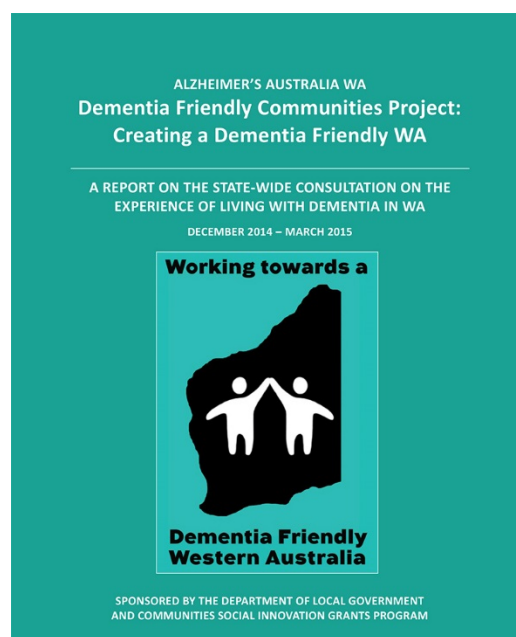
insert picture of DFC community consultation poster here

Collating and reporting the findings

Collation of the findings after the community café has taken place is an important next step. Consider the following when you are collating your findings;

- How will the findings be displayed?
- Are they in a relevant format that people living with dementia can understand?
- Does a separate document need to be developed to capture different audiences?

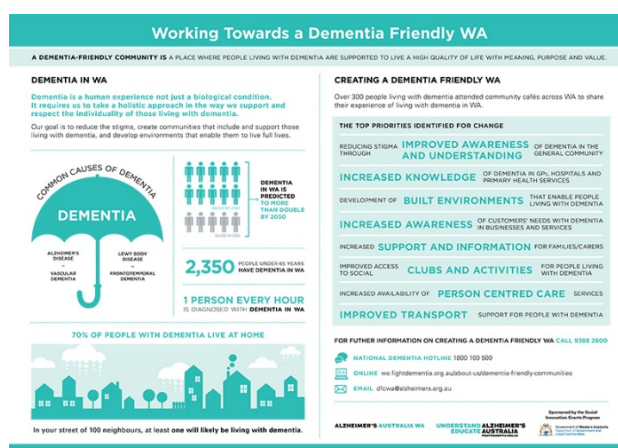
Using the example of the Alzheimer's Australia WA Dementia Friendly Communities consultation, both an info-graphic poster and a full scale report were derived from the information to allow for the different target demographics. The images below both display the separate styles of presentation. A link to the full report can be located in the resources section of this guide.



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[FIGHTDEMENTIA.ORG.AU](http://fightdementia.org.au)



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Dissemination of Findings

It is important to feed back to participants and to validate the involvement of everyone that took place in the community café. Purposeful engagement will have a ripple effect on the emotional well-being of the participants living with dementia, and will also enable positive future contact. Distributing the findings will continue to keep the community informed of the project and what developments are taking place as a direct result of the consultation café process.

Resources:

ALZHEIMER'S WA Dementia Friendly Communities Project: Creating a Dementia Friendly WA- a report on the state-wide consultation on the experience of living with dementia in WA:

www.alzheimerswa.org.au/who-we-are/dementia-friendly-communities

Public Building Audit tool and Spreadsheet:

www.enablingenvironments.com.au/audit-tools--services.html

Enabling Environments Website:

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