

DEMENTIA FRIENDLY SOCIETIES: THE WAY FORWARD

A REPORT FOR ALZHEIMER'S AUSTRALIA
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FOREWORD



As our population grows older, an increasing number of people will have dementia or some form of cognitive impairment. Currently there are more than 320,000 Australians with dementia and this is expected to increase to about 900,000 by mid-century.

As a society we are beginning to recognise the need to develop a better system of care and support for people with dementia. Last year, dementia was recognised as a National Health Priority Area, and the Gillard Government announced the “Tackling Dementia” package as part of its aged care reforms.

These reforms go some way in addressing the care needs of people with dementia and recognising the need to address dementia in both the health and aged care system.

However, we can all make a difference to the lives of those living with dementia by making our society more dementia friendly.

People with dementia and their family carers frequently tell us that from the moment of diagnosis they experience stigma and discrimination, and that social isolation increases as friends and family stop calling and visiting while invitations become increasingly rare.

Alzheimer's Australia released a report last year *Exploring Dementia and Stigma Beliefs* that found half of the respondents believed that people with dementia could not be expected to have a meaningful conversation. One third of them said people with dementia were irritating. More than one in ten indicated that they would avoid spending time with a person with dementia altogether.

I am pleased that this report, *Dementia Friendly Societies: The Way Forward*, outlines an approach to making our society more inclusive of people with dementia by developing dementia friendly communities in Australia. It provides an overview of initiatives both in Australia and overseas which promote social engagement and awareness of dementia. We have outlined a number of steps of how Australia can develop a more systematic approach to dementia friendly societies.

Last year, British Prime Minister David Cameron called for the creation of dementia friendly cities as part of his dementia challenge. He called for up to 20 cities and villages to sign up as dementia champions by 2015 and for local businesses to provide support for this concept. I am hopeful that Australia will follow the UK's lead and take an active approach to promoting social inclusion for all older Australians including those with cognitive impairment.

We need a shift in cultural attitudes, one in which we all stand ready to help people who need assistance, rather than turning our back and avoiding those who need us the most. Now is the time to take action to achieve a more inclusive society for all.

I want to thank Dr Ellen Skladzien and Kristen Holdsworth for their work on this publication.

A handwritten signature in black ink, which appears to read 'Ita Buttrose'.

Ita Buttrose AO, OBE
President, Alzheimer's Australia
May, 2013

EXECUTIVE SUMMARY

The purpose of this paper is twofold. First, to bring together the considerable information available, both in Australia and overseas, on initiatives aimed at creating dementia friendly societies. Secondly, to suggest what the next steps might be in the Australian context to foster the development of dementia friendly societies.

The concept of dementia friendly societies has emerged in countless different ways across the world but the common thread that brings these initiatives together is the desire to promote a better understanding of dementia and to reduce the social isolation and stigma that is so often experienced by the person with dementia. Stigma that surrounds dementia is simply not acceptable and we must take action to ensure that people with dementia are not excluded from society.

In Australia, a number of programs including Dementia Awareness Week, the Dementia Choir, Living with Memory Loss, the Victorian Schools Resource Kit and Side by Side are underway to educate and engage the broader community about dementia, and also to provide social support and community engagement for people living with dementia and their family members. Projects have also been developed which focus on improving physical environments for people with dementia.

Internationally, numerous programs have been implemented that aim to promote social inclusion, including the Dementia Friends Scheme aimed at training one million 'dementia friends' in the UK by 2015, the Pioneer Group which teaches school children about dementia and tackles the stigma surrounding dementia, and the Dementia without Walls project which aims to create a more dementia friendly village.

There is a risk that in setting out the initiatives that have been undertaken in Australia and overseas, the temptation will be to pick out the things that may seem easily achievable or most attractive at first glance. That is not the purpose of this publication. While we hope the readers will be interested in the diversity of different approaches and elements described in this publication, there must be recognition that integrated approaches that are tailored to local circumstances are required. A partnership approach with local community organisations and groups in the development and production of relevant resources is also essential.

Alzheimer's Australia is seeking initial discussions with the Australian Local Government Association and other organisations with a view to advancing the concept of dementia friendly societies in Australia. There are certain to be issues around the commitment and resources available to make this approach work. As a first step, Alzheimer's Australia will seek to work in partnership through the Australian Local Government Association with cities or towns prepared to develop a strategic approach that would fit their local social and physical environment.

Alzheimer's Australia may invite an international speaker in 2014 to conduct a public lecture tour on dementia friendly societies and will work with Alzheimer's Disease International and other agencies such as the World Health Organization to share experiences.

The essence of this approach is an acknowledgement that it is only through the involvement of Australians themselves that people with dementia and their families will find a greater acceptance and role in the everyday life of our society. This is what dementia friendly societies are about.

INTRODUCTION

The aim of this paper is to provide an overview of dementia friendly societies, summarise current projects in Australia and overseas, and discuss how Australia can develop further initiatives in order to better support people with dementia and become a more dementia friendly society.

Dementia friendly societies has been defined in a number of different ways; however, for the purposes of this paper we will be using the definition proposed by Davis et al. a "cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way".

Initiatives to support individuals with dementia to remain engaged in everyday life can be divided into two distinct areas of focus:

- Social environment, comprising the major cultural forces to which the individual is exposed. This includes social participation and inclusion, stigma, employment and community services.¹
- Physical environment, comprising the concrete, tangible aspects of settings that include the land, buildings, furniture and décor, whether natural or man-made. This includes public spaces, housing, and transportation.¹

WHY ARE DEMENTIA FRIENDLY SOCIETIES IMPORTANT?

Dementia is characterised by a progressive deterioration of cognitive abilities including memory, perception, verbal ability, judgment and motor coordination. In Australia, over 321,600 people are living with dementia with the number expected to increase by one-third to 400,000 in fewer than ten years.

The onset and progression of dementia has considerable implications for the individual's daily life and engagement with society. In addition to a decline in cognitive capabilities, people with dementia also experience changes in their personality and emotional state that can negatively affect their social interaction.

But perhaps even more than the changes directly associated with the disease, prevalent negative cultural attitudes and discrimination lead to social isolation.² A national population survey in Australia found that 44% of people surveyed believed that people with dementia are discriminated against or treated unfairly, with 22% indicating they would feel uncomfortable spending time with someone who had dementia.³

A recent pilot study also found evidence of stigma and discrimination.⁴ Of those surveyed, one-third of people indicated that they found individuals with dementia irritating, and 10% said that they would actively avoid spending time with people who had a diagnosis of dementia. Approximately one-quarter of the people surveyed indicated that they would avoid seeking assistance for memory problems and, for many, this was due to concerns about the discrimination they would face if diagnosed. Of those surveyed, 60% indicated that if they received a diagnosis of dementia they would feel a sense of shame, and nearly half said they would be humiliated by the diagnosis.

In addition to these considerable social issues, people with dementia also face barriers in the physical environment which affects their ability to access, negotiate, and utilise their surroundings.⁵ Complicated building designs which negatively affects way-finding and orientation, excessive signage which serves to increase confusion and disorientation, and uneven footpaths and patterned floor coverings which result in a higher incidence of stumbling and falls are just some of the challenging designs faced by people living with dementia.

The increasing prevalence of dementia demands a shift in social and physical environments to ensure those living with dementia remain included and engaged in society. The ability to engage with and contribute to the community has a substantial impact upon the individual's quality of life and is integral to maintaining autonomy and sense of self-worth. Active engagement in the community by people with dementia may also dispel the common myths about dementia frequently held by the general community.⁶

DEMENTIA FRIENDLY SOCIETIES IN AUSTRALIA

Although the term ‘dementia friendly societies’ is not commonly used in Australia, there have been a number of initiatives which have aimed to create an inclusive physical and social environment for people with dementia. Many of these programs are available only within one local community; they are often supported by one-off funding initiatives and therefore face difficulty in long-term sustainability. A selection of these initiatives are described below.

Social environment

In Australia, a number of dementia friendly projects are targeting community awareness, advocacy and social inclusion.

• Dementia Awareness Week (DAW)

This is the national centrepiece for Alzheimer’s Australia community awareness activities each year. National and local events are available for everyone and include fundraising events, conferences and special presentations as well as other dementia-related events of interest. Information about recent Dementia Awareness Week Activities can be found at <http://www.fightdementia.org.au/dementia-awareness-week-2012.aspx>

• Younger Onset Dementia Project (ACT)

The primary focus of this project was to respond to the issues raised by people with younger onset dementia and included access to age-appropriate group activities, day respite and residential respite and raised awareness of the needs of people living with younger onset dementia among service providers. Alzheimer’s Australia ACT established activity groups including a women’s group and a walking group which provided respite for carers and engaging activities for people living with dementia. In addition, Alzheimer’s Australia ACT held regular social events including dinners and cruises. The events helped to re-engage families, and promote communication about the condition among family members.

• Aboriginal and Torres Strait Islander Risk Reduction Project (NT)

Alzheimer’s Australia NT developed a risk reduction project targeting Aboriginal people. Two education sessions were provided. Session 1, What is Dementia, introduced dementia using a DVD that was specifically designed to increase awareness in Aboriginal communities and is available in English and three Aboriginal languages. The DVD was followed by an interactive discussion. Session 2 provided information on how to reduce risks using the Mind your Mind education resource and spatial puzzles and visual illusions. The sessions were provided to low-security prisoners and to people in Aboriginal drug and alcohol rehabilitation programs.

• Dementia Choir (various locations)

Choirs have been established at various locations across the country to provide people living with dementia much-needed social interaction and support. Engaging in singing activities has proven beneficial for many people living with dementia and has resulted in positive gains in social interaction and lucidity.⁷

• Ageing and Changing Project (Vic)

The Ageing and Changing school kit was launched in 2007 by Alzheimer’s Australia Vic. The kit presented a range of material that informed children and young people about dementia and the impact it may have upon them both at school and within their family. The kit also provided information for young people to help them continue their relationship with a loved one who had received a diagnosis of dementia. The school kit targeted children and young people from Prep to Year 10 and kits were provided to 500 Victorian primary and secondary schools. Feedback received from Victorian teachers revealed that 94% indicated they would recommend the kit to other teachers.

• Feros Care

Feros care conducted a telehealthcare pilot program in 2010 and utilised two telehealthcare technologies:

- 1 Telecare (smart home technologies): the use of communications-based technologies to address safety and security issues – sensors including movement sensors, fall detectors, door sensors, medication reminders, smoke and other environmental sensors, and emergency pendants were fitted to 30 client homes.
- 2 Telehealth (home monitoring technologies): the use of communications-based technologies to monitor chronic and degenerative conditions – devices including blood pressure, pulse and oxygen saturation monitors, weight scales and glucometers, and targeted ‘interviews’ customised for each client’s conditions were implemented in 15 client homes.

The project improved client wellbeing with participants feeling they could better care for themselves, having less fear and anxiety about having an undetected fall, and improved ability to manage household tasks. Participants in both groups reported that the technology was easy to use, devices were non-intrusive, and the technology improved their quality of life.

- **The Caregiving and Dementia Wiki Project (Dementia Training Study Centre)** (NSW)

The aim of the project is to develop free and open resources about vital aspects of psychosocial care for people with dementia. The project utilises the Wikimedia Foundation (WMF) platform.

- **Living with Memory Loss** (Australia-wide)

This program is designed to support people in the early stage dementia; a family member/friend/carer is welcome to accompany them. Participants have an opportunity to obtain information, talk confidentially with others in a similar situation, focus on maintaining and enhancing skills and abilities, and explore ways of managing now and in the future.

Topics covered include:

- symptoms and diagnosis
- adapting to change
- practical strategies
- looking after yourself
- planning for the future.

- **Side by Side Program** (SA)

This workplace engagement program is run by Life Care in conjunction with Bunnings Mile End; it supports individuals with younger onset dementia to take on a range of work activities. The individual living with dementia is supported by a workplace 'buddy', a volunteer from the store who has received dementia training. The program also serves to raise awareness of dementia among staff through training and also the broader community via an information booth located at the store.

An evaluation of the Side by Side program revealed a number of positive outcomes for participants and their family members, including improved self-esteem, an increase in mental alertness, and an increased interest in life more generally as a result of participation in the program.⁸ The project also provided the person with younger onset dementia with an opportunity to connect with people in a similar position and provided family carers with regular respite in an environment comfortable to the person with younger onset dementia.

- **Memory Lane Cafés** (Vic)

The Memory Lane Cafe Program is a support program funded by the Australian and Victorian governments, under the Home and Community Care Program. The cafés provide an opportunity for people with dementia and their family members to enjoy time together with some refreshments and entertainment, in the company of people in a similar situation to themselves.

- **Memory Books Project** (NSW)

This project was a collaboration between Holdsworth Community Centre and Services and the Kambala Girls School. Students were prepared with knowledge about dementia. Family carers were asked to collate information about the person with dementia, such as favourite photographs and other memorabilia for the students to place in a memory book. This information was presented to students by the carer and the person living with dementia enabling them to tell their stories to students. The project served to raise awareness with students, in a relaxed setting, about dementia and the role of carers.

- **Count Us In** (Vic)

The aim of Count Us In was to establish and evaluate a playgroup in an aged care facility. A playgroup was held once a week for 1.5 hours over six months at a low-care facility with 11 residents participating in the project and 12 children aged five months to three years also in attendance. Indoor and outdoor activities were arranged with two special events including an animal farm visit to the facility and an event at the Botanic Gardens.

Resident, parent and staff evaluations were conducted pre- and post-playgroup with the number of residents indicating they were in good health increasing by 7 per cent, and a 25 per cent increase in the numbers of residents who felt valued as a person. All residents and staff who completed post-evaluation surveys indicated the playgroup was worthwhile for residents, families and children, and indicated their wish for the project to continue in the future.⁹

DEMENTIA FRIENDLY SOCIETIES IN AUSTRALIA (CONTINUED)

Physical environment

Although substantial information is available about best practice design for indoor environments, studies have revealed that these principles are rarely adopted even in newly designed facilities.¹⁰ Some initiatives in this area which aim to improve design for people with dementia include the following:

- **Dementia Enabling Environment Project (DEEP)**
Alzheimer's Australia is working to address the gap between existing research about dementia friendly environments and current design practices via a project which is funded through the Alzheimer's Australia's National Quality Dementia Care Initiative (NQDCI). This national project aims to translate research into practice in the area of enabling environments for people with dementia. One aspect of the project is a website that serves as a clearing house for information on best practice guidelines as well as providing audit tools for dementia design. These resources can be found at <http://www.enablingenvironments.com.au/>
- **Dementia Sensory Garden** (Australia-wide)
Bupa Australia has opened a number of specialised gardens in its aged care facilities. The 'backyards' concept which is utilised for the gardens includes destinations which are familiar and comfortable to people. For instance, a number of the 'backyard' gardens include things such as a mailbox, raised garden beds, a clothesline, a dad's shed and a chicken coop. These elements are designed to engage people with dementia and involve them in familiar domestic activities. Further information can be found at <http://www.bupaagedcare.com.au/about-us/news/people-with-dementia-don%E2%80%99t-receive-adequate-care-within-the-community>

• Assistive technology (WA)

A wide range of assistive technology is currently available to assist people living with dementia to remain independent for as long as possible. Alzheimer's Australia WA provides advice on a variety of assistive technology equipment suitable for dementia care, and provides information sheets to describe the equipment as well as purchasing information. These products are also featured in the Alzheimer's Australia WA Assistive Technology demonstration room. Categories of products include:

- prompts and reminders: clocks, pill box alarms, automatic medication dispenser, and fridge recorder
- sensory: therapeutic dolls, Fiddle Twiddles, and robotic pets
- communication: talking photo album, Safe2walk personal alert and GPS locator
- safety: door alarms, cabinet locks, stove guard, and water alarms to prevent flooding
- monitoring systems: emergency ID bracelets and pendants, wander alarms, and PANDAH (personal alert night and day at home) which sends automatic SMS messages direct to carers' mobile phones when assistance is required
- everyday living: coloured toilet seats, automatic safety iron, bathing aids, and dinner sets.

Further information can be found at <http://www.fightdementia.org.au/western-australia/assistive-technology--product-information-sheets.aspx3>

- **Dementia Training Study Centre (NSW/ACT)**

This centre has produced considerable work on the built environment including the following:

- *Built Environment Audit Tool – Dementia (BEAT-D) iPhone/iPad app*: BEAT-D aids in the assessment of residential care environments for people with dementia. The app acts as a guide through the use of the environmental audit tool, allows photographs of key parts of the environment to be taken and sends data for processing. A report comparing the facility with 56 other facilities and identifying areas for improvement is then emailed along with an invitation to discuss the results with an expert in the design of facilities for people with dementia. This service is provided by the NSW/ACT Dementia Training Study Centre which is supported by the Department of Health and Ageing.
- *Environmental design consultancy*: This service provides education and advice to aged and healthcare managers who are in the process of planning new, or refurbished, facilities for people with dementia; it is available Australia-wide. The NSW/ACT Dementia Training Study Centre has been funded by the Department of Health and Ageing to provide the service to 75 aged or healthcare providers. The consultancy service includes on-site consultation for a day, discussion of evidence-based design principles, design assessment, and discussion and recommendations.
- *Environmental design guest lectures and workshops*: Workshops are interactive with a focus on best-practice design principles in planning/establishing facilities for people with dementia, including methods for identifying the strengths and weaknesses of facilities for people with dementia and examples of ways to improve facilities.

Further information can be found at: <http://dtsc.com.au/new-south-wales-australian-capital-territory/projects/>

DEMENTIA FRIENDLY SOCIETIES OVERSEAS

The concept of dementia friendly societies is receiving considerable interest overseas with a host of initiatives currently underway. The UK is leading the way with British Prime Minister David Cameron issuing a national challenge on dementia in March 2012 which included a focus on creating dementia friendly societies. This has resulted in a range of projects in both the physical and social environments with the support of countless organisations and towns.

Social environment

Social initiatives include the following:

• **Dementia Friends scheme** (UK/Japan)

The UK government aims to train one million people by 2015 to become 'dementia champions'. Education sessions in workplaces and town halls across the country will explain what dementia is, what it is like to have the condition and what people can do to help if they meet someone with the symptoms.

Similarly in Japan, the 'Nationwide Caravan to Train One Million Dementia Supporters' program aims at training, in the next five years, one million 'dementia supporters' who understand the characteristics of the disability and provide support for afflicted persons and their families. Through its training courses, 694,854 dementia supporters were trained nationwide as of 2008.

• **The Pioneer Group** (England)

Twenty-one schools have formed a 'Pioneer Group' to develop dementia awareness sessions for children and young people across England. This project developed because of the recognition that the effects of dementia extend beyond the person living with dementia to their families, and younger people are often forgotten in this. The project has the potential to establish dementia friendly generations.

The aim of the dementia awareness sessions will be to educate children and young people about dementia, remove stigma and provide the opportunity for interaction with people with dementia.

• **Dementia Without Walls Project** (England)

This project combines both the physical and social facets of dementia friendly societies. The project enlisted the help of people living with dementia in identifying factors that determined whether York was, or could become, dementia friendly. The project utilised the four cornerstones model for realising a dementia friendly community: 1) place, 2) people, 3) resources, and 4) networks. The project successfully identifies multiple opportunities for making York a dementia friendly society.

• **Dementia Friendly Organisation** (UK)

Other initiatives are underway in England as a result of the Prime Minister's national challenge on dementia. They have incorporated numerous organisations including the retail sector, financial institutions, emergency services, energy providers, and transport. This has involved training of staff as well as collaboration between organisations and the Alzheimer's Society to create resources and help sheets to assist staff to respond to the needs of customers living with dementia. Further information can be found at <http://dementiachallenge.dh.gov.uk/2012/11/08/dfcachievements/>

• **Together for a Dementia Friendly Bruges** (Belgium)

This large-scale project aims to raise awareness in the broader community as well as fight stigma associated with a diagnosis of dementia. The project endeavours to improve the lives of people living with dementia by bringing about change in citizens, businesses and organisations, and officials, which will lead to more respectful communication and interaction. At initial consumer meetings involving schools, societies, the hospitality industry and the cultural sector, a five-year action plan was established. The project has a number of key areas including:

- *A dementia expertise centre*, which provides information, advice and training to professional caregivers and fosters cooperation between all relevant partners in dementia care. The centre has been successfully running for over 15 years.
- *An accessible walk-in house* where a host of activities are available. The house is run by ten volunteers who provide one-on-one contact for consumers. Activities at the house include meeting groups, music afternoons where visitors can enjoy a cup of coffee and listen to music and meet others, literary evenings for professionals and consumers, a choir lead by a counsellor and two voluntary musicians, and season celebrations including Easter and Christmas.
- *A symbol* of a knotted handkerchief is displayed in windows of local businesses to indicate to those with cognitive impairment and dementia that they will receive an empathic reception.

- **Home from Home** (Ireland)

This is a unique service that increases the range of choice for those who need day-care. The project involves people in the community who offer hospitality in their homes to a small group of people with dementia for a day or more on a weekly basis. The service provides the person with dementia with a stimulating and enjoyable experience in a home environment where there is an opportunity to talk and reminisce, share a meal together and be with people who understand.

- **Friends of the Elderly Transition Year Program** (Ireland)

The aim of this program is to provide an opportunity for the young and the elderly to enjoy each other's company by sharing knowledge and companionship. The program involves making a friendship commitment to an elderly person, designing and making friendship cards for the elderly, producing a 'Life and times biography' for an elderly person, and producing a 'When my elderly friend was young' essay. The program is also offered to classes or for the school year with a Certificate of Merit issued by the President of Friends of the Elderly Ireland upon completion. For further information, go to <http://www.friendsoftheelderly.ie/schools-programme/secondary-schools-programme.html>

- **Dementia Friendly Hospitals** (United States)

This project was conducted in four hospitals in the US with over 500 participants. The project targeted nurses and other direct-care staff, including social workers, physical therapists and pastoral carers working in hospitals, and provided them with information and other resources to improve care for patients living with dementia.¹¹ Increases in staff knowledge, confidence and care practice were reported post-training and the program also resulted in cultural changes within institutions.

Staff often noted that lack of time with dementia patients was an issue, as were the need for supplies and activity items. This resulted in the development of activity kits for dementia patients. One hospital created a team of volunteers especially trained to assist in the care of a hospitalised person with dementia. The volunteers provided companionship, alerted nurses if the dementia patient tried to do something unsafe, and provided activities.

- **Dementia Friendly Communities** (Scotland)

This project has brought together a group of likeminded people in the East Sutherland region in order to turn their local county into a more dementia friendly community. The dementia friendly group will be working towards:

- working collaboratively with local services and businesses to assist local communities to become friendly and fulfilling places for people with dementia and their family members
- ensuring participation by people with dementia in their chosen activities by increasing local opportunities
- increasing the support for dementia carers by creating a shared understanding of the emotional and practical challenges faced by carers
- challenging the misconceptions and stigma associated with dementia.

A number of online resources and virtual meeting places have been developed as part of this approach in order to share experiences, views and support. These include:

- Carer's Voice, which offers support to dementia carers
- A Care Home Voice, which is a forum for care staff, residents and families to share ideas and information regarding best practice in residential dementia care
- A Dementia Voice, which is a platform for people living with dementia to share their story and receive support
- Dementia friendly communities, whose flagship site will detail the progress made in dementia friendly communities.

DEMENTIA FRIENDLY SOCIETIES OVERSEAS (CONTINUED)

Physical environment

Current projects overseas include the following:

- **Dementia Friendly Hospital (UK)**

Nurses and doctors at Southampton Hospital have created a 'dementia friendly' ward which uses colours and images to create a more suitable environment for dementia patients. Doors in the ward were painted bright colours and bed numbers were replaced with images such as umbrellas or lighthouses to help patients remember which bay they are staying in. The nurses' station has been renamed 'reception' and lowered to improve accessibility and to put patients at ease when approaching. For further information, see <http://www.nursingtimes.net/hospital-pioneers-dementia-friendly-innovations/5049349.article>

- **Design for Dementia: improving dining and bedroom environments in care homes (UK)**

The aim of this project was to create environments that maximise the existing abilities of the residents, promoting independence and improving their experience of living within the building.

By designing physical environments that help residents with dementia complete tasks such as dressing or eating, their quality of life could be improved and the staff workload reduced. The focus was on low cost modifications which included:

- inclusive table designs (wheelchair friendly, square designs)
- assistive tableware (to assist residents with low-vision or issues with dexterity)
- clothes display hangers (whole outfits stored on one hanger)
- content visible drawers.

For further information, see <http://www.hhc.rca.ac.uk/2988-3029/all/1/Design-and-Dementia.aspx>

- **Improving the Streetscapes (UK)**

This is an independent project being conducted by the York Civic Trust. In recent years, it was noted that York's streetscape had become seriously degraded by poles, signs, bollards, inappropriate paving, cycle tracks, poor streetlights, road humps, and double yellow lines, all of which can make navigating streets difficult for pedestrians and drivers. Although the project is not specifically aimed at people with dementia, it has important implications as many of these (for example, the overuse of signage, inadequate lighting, and uneven footpaths) pose considerable difficulties for people with dementia. For further information, see <http://www.yorkcivictrust.co.uk/?idno=695>

THE WAY FORWARD WITH DEMENTIA FRIENDLY SOCIETIES

There are a number of localised initiatives in Australia that aim to create a more inclusive society and to implement appropriate design principles. To date, however, there has not been an adoption of the idea of creating 'dementia friendly' cities or communities such as has occurred in the UK.

A number of Australian cities have adopted the World Health Organization (WHO) guidelines on developing an age-friendly city, but these principles do not necessarily address key issues for people with dementia.

A similar approach could be taken to developing a set of international guidelines for dementia friendly societies or dementia friendly cities.

The UK has developed an online recognition process for Dementia Friendly Communities after extensive consultation with consumers. In the consultation process the consensus view was the best approach was to develop a set of flexible standards that could be adapted to fit each community or setting while avoiding an overly technical assessment process that would deter communities from adopting the approach.¹² A symbol was developed to denote communities that are 'working towards becoming dementia friendly'. This is recognition that there is no absolute standard and that each community will take an ongoing approach towards creating a more dementia friendly environment.¹²

The UK Alzheimer's Society has developed a set of values and standards to guide the development of dementia friendly communities (see Appendix 1). In order to qualify for recognition as a dementia friendly community, organisations or communities must describe the specific actions they plan to take to implement the standards as well as to undertake ongoing annual self assessment of their progress towards achieving the standards. They are required to involve individuals with dementia and their carers in the self assessment process.¹²

The Alzheimer's Society will hold the copyright to the symbol denoting a dementia friendly community/organisation. It will grant permission to use the symbol to communities or organisations that sign up to the recognition process. They retain the right to withdraw permission if it is felt that the community or organisation is not meeting the conditions of the program. Although the Alzheimer's Society has responsibility for oversight they also encourage local oversight. The Society indicates that responsibility for committing to the standards should be taken by the local dementia action alliance where possible or a similar group. If this is not feasible, a named senior figure must take responsibility.¹²

Australia could undertake a similar process of consultations to develop guidelines and standards for dementia friendly communities and organisations. The materials developed by the UK provide an excellent starting point for consultations. The goal should be to develop similarly high level flexible guidelines that promote an approach to developing a more dementia friendly society but do not create excessive administration or inflexible guidelines that deter communities from being involved.

NEXT STEPS

Subject to receiving support and funding Alzheimer's Australia will take its work on dementia friendly societies forward on the following basis:

- i Alzheimer's Australia to seek to work in partnership through the Australian Local Government Association with cities and/or towns prepared to consider and develop a strategic approach that would fit their local social and physical environment. This approach could be modelled after the work that has been done in the UK.
- ii Alzheimer's Australia will host an international speaker from the UK to conduct a public lecture tour in 2014 to discuss the approach to dementia friendly societies in the UK. This tour could be accompanied by a publication which provides specific recommendations for implementation in Australia.
- iii Alzheimer's Australia will conduct a consultation process to develop a recognition process for dementia friendly communities and organisations in Australia based on the work done in the UK.
- iv Alzheimer's Australia will work with other organisations including the World Health Organization and Alzheimer's Disease International to share experiences.

APPENDIX I¹

Alzheimer's Association UK Values and Standards for Dementia Friendly Communities and Organisations

Values

We believe that people with dementia and their carers have the right to:

- 1 Live their life in a way that meets their needs.
- 2 Engage in and contribute to their local communities as long as they wish to do so
- 3 Live alongside people who have an awareness and understanding of dementia.
- 4 Live their lives free from stigma.
- 5 Access the information, support and services that they need.

Standards

There are separate standards for communities and organisations, detailed below.

A community

Our community is *working towards*:

- 1 Developing a local Dementia Action Alliance (or a similar group). To include the support of a recognised, senior local leader(s) for example, a head of local business or a local council leader.
- 2 Analysing the key issues to address to enable them to become dementia friendly in ways that are important to people with the condition and carers.
- 3 Involving people with dementia and their carers in understanding what dementia friendly means and in the self-assessment process.
- 4 Identifying which individuals, businesses and organisations are a priority to undertake dementia awareness and understanding training.
- 5 Providing information on dementia and available services and support from a range of outlets (as considered appropriate, for example library, pharmacy or GP surgery).
- 6 Seeking to share information and learning with other organisations or communities working to become dementia friendly.

An organisation

Our organisation is *working towards*:

- 1 Ensuring the support of senior members of staff, for example a manager or director.
- 2 Analysing the key issues to address to enable them to become dementia friendly in ways that are important to people with the condition and carers.
- 3 Involving people with dementia and their carers in understanding what dementia friendly means and in the self-assessment process.
- 4 Identifying ways to raise dementia awareness and understanding amongst appropriate personnel.
- 5 Providing information on dementia and available services and support (as appropriate to the organisation).
- 6 Seeking to share information and learning with other organisations or communities working to become dementia friendly.

¹ from Alzheimer's Society. (2013). Response to the consultation on the recognition process for dementia friendly communities.

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