People with younger onset dementia, which can cause vision impairment, walking in Jells Park as part of a partnership between Alzheimer’s Australia Vic, Parks Victoria and Blind Sports Victoria.
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It was Mahatma Ghandi who said that “the true measure of any society can be found in how it treats its most vulnerable members”. While many variations of this sentiment have been quoted throughout history, care for the welfare of others, equality of opportunity and fairness remain core Australian values.

People living with dementia are among our society’s most vulnerable, and it is widely acknowledged that, following a diagnosis, many experience increased isolation. With our population ageing and with dementia now the second leading cause of death in Australia, the time to ready Australia for this growing challenge is now. At Alzheimer’s Australia we firmly believe that making society more understanding of those with a cognitive impairment and improving the accessibility of a community’s physical environment is beneficial to the entire population. Those most vulnerable in our society may benefit the most from change, but everyone stands to gain from living in a society that’s more tolerant, easier to navigate, and designed to cater to a wide range of needs.

That’s why we believe so strongly in creating dementia friendly communities that support those living with dementia to remain engaged, included and connected.

There is no cookie-cutter approach to becoming a dementia-friendly community: it is something that has to be developed to meet local needs and it has to be owned by locals, especially those with dementia and their families and carers. However, Alzheimer’s Australia has a broad national network of resources to help willing communities become leaders in providing a place where those living with dementia are supported to live a high quality of life with meaning, purpose and value. We also have a growing list of communities around the nation that have become showcase towns, realising the practical benefits for their residents of becoming dementia-friendly. The New South Wales towns of Port Macquarie and Kiama are leading the way, even as others around the country begin to pilot their own dementia-friendly communities.

In Victoria, communities will be supported in their drive to become dementia-friendly through a world-leading Virtual Dementia Experience™ that visually demonstrates how a person living with dementia may experience common environments. This powerful tool, based in Melbourne, has been acclaimed as an excellent way to build understanding of dementia and highlights how simple adaptions to a room may dramatically improve the life of a person with dementia. This experience is currently being developed further to allow us to make it more portable and able to be demonstrated to communities across Australia. This paper outlines the current and emerging needs, and importantly the opportunities that exist for communities that achieve a ‘dementia-friendly’ status.

I strongly encourage our political, business and community leaders at local, state and federal levels to provide the passion and support needed to create more dementia-friendly communities across Australia. While funding of start-up programs must usually come from government, change begins with all of us and I encourage everyone to work towards realising the benefits that come from creating a more inclusive society.

Carol Bennett - CEO
Alzheimer’s Australia
2 EXECUTIVE SUMMARY

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.\(^1\) 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 disease.\(^2\)

As Australia’s population ages and life expectancy grows, conditions such as dementia will play an even greater role in our society over the coming years.

The 2015 Intergenerational Report highlights the economic impact of an ageing population, bringing to the fore the need to make progressive changes now to be ready for a greater proportion of older Australians living in our communities. The number of Australians aged over 65 years is expected to more than double by 2055. Female life expectancy is also projected to increase from 93.6 years now to 96.6 years in 2055. Australian males are expected to live to 95.1 years over the same period, up from 91.5 years today.\(^3\)

As our population ages, dementia rates too are expected to significantly increase. By 2020, about 400,000 Australians are projected to be living with dementia.\(^4\) By 2050, close to 900,000 people across the country are forecast to be living with dementia.

The need to physically and socially prepare our communities for an older population, and to understand issues affecting the elderly, has never been greater. Communities that make moves toward embracing our demographic shift will have a significant advantage over other areas and stand to gain not only from greater social cohesion but also economically.

The development of dementia-friendly communities across Australia will dramatically improve the quality of life for people living with dementia, as well as their carers, family, friends and broader support networks by helping to break down the stigma often associated with the condition. And the very act of creating dementia-friendly communities is a process of engagement: people with dementia should be at the centre of all planning, consultation and activities.

However, dementia-friendly communities can also offer benefits to the wider population. The promotion of social cohesion and understanding the needs of others helps make these communities generally great places to live, aiding in their growth and prosperity. Flow-on benefits to businesses that promote themselves as more accessible to people with dementia and other cognitive impairments are likely to be realised as more people – especially the elderly – see these as welcoming places to visit and shop. As many areas seek the tourism potential of the growing ‘older affluent’ travel market, those towns able to promote themselves as easy to navigate, dementia-friendly, and genuinely welcoming communities will have a major advantage in attracting older visitors over places that do not meet these criteria.

While the major benefits of dementia-friendly communities are social and quantifiable in the positive feedback given by people with dementia, their carers and community participants who have seen the improvements, there are also very tangible economic benefits. These benefits are realised to the greatest degree in potential savings to state, territory and federal health budgets through earlier diagnosis and support for people to live more actively within their communities and reduce dependency on the aged care system and acute care.

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\(^1\) Alzheimer’s Australia Vic (2014), ‘Creating a Dementia-Friendly Community for the City of Melbourne’, March 2014, p.2
\(^4\) Alzheimer’s Australia, ‘Creating dementia-friendly communities: A toolkit’
“Deaths from dementia and Alzheimer’s disease have been increasing in number for many years, and now outrank Cerebrovascular diseases as the second leading cause of death of Australians. There were 11,000 deaths from dementia and Alzheimer’s in 2013, an increase of over five per cent in the past year and over 30 percent in the past five years.

“Advancements in treatment of circulatory diseases have decreased the number of deaths from these conditions. As life expectancy increases (now at 80.1 years for males and 84.3 years for females) it is likely the number of deaths from dementia will continue to grow.

“These large scale shifts in patterns of mortality provide critical insights into the multitude of factors which impact on the health of Australians.”

A dementia-friendly community is a place where those with dementia and their families and carers are understood, supported and able to actively function as part of that community. To achieve this, people with dementia, their families and carers must be involved from the outset. But those living in the community must also be well informed to help reduce the stigmas and myths surrounding dementia and to promote respect and empathy.

While education and awareness play a very important role, practical support services must also be put in place to help those with dementia live as full a life as possible.

A community that embraces a dementia-friendly approach not only demonstrates its support for those with dementia, but the vulnerable members of its society more generally. Improvements to the physical environment of a precinct, suburb or city designed to help those with dementia will benefit everyone with ease of access, safety and navigation enhanced.

Such values not only enrich the social fabric of the community as ‘the right thing to do’, but have wider, practical benefits to the area by making them engaging, attractive places to live. A community recognised as dementia-friendly indicates to locals, new residents and visitors that it is a safe and welcoming place in which to connect with others and do business.

Dementia-friendly communities – and recognition of their benefits – are gaining international recognition and momentum, with communities of different forms existing in the United Kingdom (in several areas including York, Hampshire and Sheffield), the Netherlands, Japan and Belgium. In Australia, Port Macquarie and Kiama in New South Wales have been exploring dementia-friendly principles since 2013, while pilot projects are also underway in Darwin (NT), Holdfast Bay (SA), Bribie Island (Qld) and Beechworth (Victoria).

Each pilot community works to achieve buy-in from a multitude of local stakeholders and develop Dementia Action Plans that can include changes to the streetscape and public buildings, a focus on peer support services for people with dementia, their families and carers, and widespread awareness and education for the general community. Although the commitment and contribution of the local teams has been truly remarkable to date, there is no doubting that pilot funding has contributed to the success achieved so far. It is also clear that even small funding boosts have lasting and significant effects within a given community: the financial support for specific shorter-term initiatives has been shown to lead to further activities and community buy-in – which in turn ensures that dementia-friendly principles are incorporated into longer-term strategies and policy platforms.

3.1 THE KEY INGREDIENTS

No two suburbs or towns are alike, and the same can be said for dementia-friendly communities. Locals including, of course, people with dementia, identify ways to improve access to their services, build connectivity and break down attitudinal barriers. Signage, ticketing and information services for bus and train operators may be a priority in a large city well served by public transport. However, in smaller regional towns locals in Australia and overseas have rather identified the need to work closely with taxi drivers and to develop dementia and driving tools where car dependency in regional areas is significantly higher. In more remote parts of the UK, locals have addressed the need to raise dementia awareness with search and rescue authorities.

While the implementation of a locally-developed Dementia Action Plan will vary from community to community, the UK and Australian experience has so far identified a few key ingredients needed for the successful roll-out of the program:
1. **Strong local government support at a senior level** – Local councils are not only responsible for the delivery of many services residents come to depend upon, but they are well-connected to the needs of their community and in a position to communicate effectively. The most successful of the UK dementia-friendly communities typically see a supportive council leader driving the program across all municipal departments and the Australian experience reflect the same principles. Projects in South Australia, the Northern Territory, Victoria and New South Wales have all benefitted from close ties to the applicable local council.

2. **A powerful community leader** – A respected leader that brings community values to the fore is needed in the developmental stages to bring together diverse groups, paint a picture of the need and explain the benefits of dementia-friendly communities. In Port Macquarie, the NSW State Member of Parliament Lesley Williams was instrumental in building the early links across the community. In Victoria, the Beechworth pilot is actively championed by the Federal Member for Indi, Cathy McGowan AO. The creation of a sense of urgency and formation of alliances and partnerships across a wide range of community groups, the business sector and government is crucial.

3. **A dedicated Project Officer resource** – Coordination of individuals and groups to meet the objectives of the Dementia Action Plan is needed to prioritise resources, training and ensure evaluation is undertaken. A Project Officer also works directly with people with dementia, their carers and support networks to identify local needs and provides crucial links between stakeholders.

4. **Engagement of people with dementia in all elements of the project** – The strength and success of any dementia-friendly community project rests on the active involvement of people with dementia – as committee members, as volunteers, as formal or informal consultants or as interested community members. It is those with dementia who are best placed to identify the types of priorities that are important within a given community.

5. **Local willingness** – The support of major businesses at a corporate level in the UK were important catalysts; however those that were able to trickle down their training to the local level were the most successful in creating real change in their communities. Towns or suburbs with a strong desire to be more inclusive and break down negative stereotypes are more likely to deliver successful dementia-friendly programs. The formation of local dementia alliances in all of the pilot sites has facilitated community conversations and the buy-in of such segments as retail, health services, tourism and community services sectors. In Darwin, hospital staff have been enthusiastic supporters, while in Holdfast Bay aged care provider interest has been matched by community based organisations.

6. **Support from a research body** – Universities in particular have been valuable partners in the most successful dementia-friendly communities, by helping to establish metrics, providing evaluation services and other research expertise to demonstrate tangible benefits and feedback to allow ongoing refinement. Beechworth, for example, has partnered with Alzheimer’s Australia Vic to survey participants and is working with La Trobe University and Charles Sturt University to develop evaluation frameworks. Kiama also has a close partner in the University of Wollongong.
The Beechworth pilot in Victoria is an excellent example of a community that deploys all of these elements. It has buy-in from all parts of Indigo Shire Council, including at CEO level. Passionate local community member Joan Simms has provided leadership to drive systemic change in Beechworth in addition to project champion and Victorian MP Cathy McGowan, who advocates in the community as well as in Parliament. The local willingness of the supermarket, bank, bowls club, Probus Club, Red Cross, Lion’s Club, University of the Third Age, Victoria Police, bus and taxi service, and neighbourhood centre to be involved has also been integral. Support from La Trobe University and Charles Sturt University in measuring and evaluating the impact of initiatives also lends valuable research expertise to enable the ongoing refinement of the program.

Any community may become dementia-friendly, although those with the abovementioned attributes have a greater likelihood of success. In choosing future pilot locations across Australia, these qualities will be highly sought, along with consideration of the area’s demographics. While not essential, an older population and/or high incidence rate of dementia in a community may be a constituent driver in a community’s willingness to explore dementia-friendliness. For instance, Port Macquarie was chosen in part because it had the second highest prevalence of dementia out of New South Wales’ 93 electorates. In the case of Beechworth, its federal electorate of Indi was ranked number 20 of the Victorian seats where dementia was most prevalent in 2015.

“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, Chair, Alzheimer’s Australia Dementia Advisory Committee.

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Source: Alzheimer’s Australia national office


8 Kate Swaffer presentation, Alzheimer’s Disease International Conference, Perth, Australia, April 2015
**CASE STUDY**  
**PORT MACQUARIE: A DEMENTIA-FRIENDLY CITY**

Through the local service provider network, people living with dementia and their carers were asked to share their stories in the local media, thereby raising awareness in the general community about the impact of dementia and helping to increase the sense of urgency.

A Steering Committee was formed … and focus groups for people living with dementia and their families were held in Port Macquarie to gain input into what a dementia-friendly community might look like. One strategy agreed by the Steering Committee members was to publicise the ‘Is it Dementia?’ education resource (a series of videos online) to local businesses so that staff could be made more dementia aware.

A submission was made to the local council’s Draft Town Green Masterplan and the Town Square Masterplan to make seating, signage, and colour contrast recommendations and spanning such elements as public toilets. The implementation of the Men’s Shed project in the Hunter region of NSW was expanded to include Men’s Sheds in the Port Macquarie region. Dementia awareness information sessions were provided to local council staff and also to volunteers who could then run dementia awareness sessions for the broader community and for their own social groups and club networks.

Port Macquarie is still in the early stages of moving towards become a dementia-friendly community; however, dementia awareness is becoming part of the Steering Committee members’ ‘core business’ and is being embedded into the various organisations’ consciousness.

Adapted from extracts from ‘A guide to becoming a dementia-friendly community’, Alzheimer’s Australia report, September 2014
4 BENEFITS OF CHANGE: WHY BECOME DEMENTIA-FRIENDLY?

Dementia-friendly communities around the world have proven to deliver a wide range of social and economic benefits to the areas that have embraced change. Most notable of course is the positive impact on the life of a person living with dementia, as negative stereotypes are broken down and support services are put in place to enable people to remain active members of their community. However, there are wider benefits for all residents that come from living in a more inclusive, tolerant and accepting society, including the social and economic benefits associated with being a dementia-friendly community.

4.1 BENEFIT TO PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS

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 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 stigma.9

A 2012 Alzheimer’s Australia study about stigma and dementia found:

- 22% of those surveyed said they would feel uncomfortable spending time with someone who had dementia;
- 34% of respondents found people with dementia to be irritating;
- 11% said they would avoid spending time with people who had dementia; and
- If diagnosed with dementia, 60% anticipated that they would feel shame.10

These attitudes are echoed by a 2014 survey of people with dementia, where over half of all respondents felt that others avoided spending time with them because of their diagnosis. Almost half wished they had more social contact with people in the community.11

These figures show that we still have a long way to go before we become a more tolerant and welcoming society for people with dementia. Attitudinal change, active participation and enabling policies that are the hallmark of dementia-friendly communities have proven to greatly enhance the lives of people living with dementia.

4.2 ECONOMIC BENEFIT TO BUSINESS

Dementia-friendly businesses typically make alterations to their physical environment, which improve navigation for all patrons and makes them generally popular places of trade. German supermarkets that have embraced the concept have seen the installation of “better lighting, wider aisles, non-slip floors, large price labels and smaller packages to make goods easier to handle … magnifying glasses on chains hang from shelves and red help buttons are located around the stores”12. This has made them popular not just for those with dementia, but the elderly more generally, who see such initiatives as welcoming and deserving of their business. In the United Kingdom, dedicated ‘dementia-friendly’ bank tellers have noted increased traffic as people with dementia but also older patrons or those who don’t wish to be rushed choose to utilise their services.

As our population ages, measures to improve accessibility in the retail environment may initially provide a competitive advantage, though over time they will become a financial imperative to businesses who must attract and support elderly patrons. As dementia-friendly principles are incorporated into longer term planning, the cost to the community and governments is greatly decreased as design enhancements become mainstream.

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9 Alzheimer’s Australia Victoria 2015-16 (Victorian) State Budget Submission.
11 Alzheimer’s Australia (2014) Living with Dementia in the Community: Challenges and Opportunities.
4.3 Economic Benefit to Tourism

A dementia-friendly community status indicates to tourists that a town or city is inclusive, welcoming and has given considerable thought to how locals and visitors alike navigate the physical environment. This is potentially very attractive to the older, affluent travel segment who are highly sought after for their spending power and greater length of stay when travelling.

Tourism is an important part of the national economy. Tourism leaders throughout Australia have identified the ageing population as “an opportunity to target older … empty nesters, semi-retired and retirees who have more time and interest in travelling to distant regions … importantly, outside of peak times such as public and school holidays”13, making this an important tourism segment. Towns that position themselves as welcoming of older domestic visitors by actively promoting a dementia-friendly community status have the potential to gain from the patronage of this key segment.

4.4 Economic Benefit to Health Budget

Living in one’s own home and community as long as possible, without the need to move to a residential aged care facility, is the desire of the vast majority of aged people, including those living with dementia.

However, it also makes good economic sense, with governments worldwide seeing the benefit of supporting people to live sustainably within their communities for as long as possible. The National Commission of Audit estimated that Commonwealth expenditure on aged care was around $13 billion in 2013-14, and that this would “increase by around 4.9 per cent each year over the next decade in real terms. In 2023-24 it is estimated that the Commonwealth Government will spend over $26 billion on aged care”.14 The Commonwealth Department of Finance noted that 82 percent of this funding went to residential care in 2012-13.15

The cost of replacing the informal care of loved ones at home with formal (paid) care at a residential facility is also significant. Across all types of care requirements (not just dementia), Carers Australia estimated that the annual ‘replacement value’ of informal care exceeded $60 billion per annum.16

The support of a community for those living with dementia also has potentially major economic benefits to the acute care system if that support helps to ultimately reduce hospital admissions. The National Health and Medical Research Council’s (NHMRC) Hospital Dementia Services Project found that a person with a diagnosis of dementia spent more than twice the amount of time in hospital (19.6 days) compared with all hospital separations (8.6 days). That figure more than triples for someone with a principal diagnosis of dementia to 30.1 days.17

While not specific to dementia, a joint Curtin University and University of Western Australia study found that “receiving a reablement (restorative) service in comparison to a conventional home care service reduced the likelihood of using any home care service for the next three years and the need for a personal care service for nearly five years”. The study found that a median cost saving of approximately $12,500 per person over nearly five years could be achieved.18 Dementia-friendly communities are typically designed to support this reduced use of home care services, and as part of a broader support network, help people with dementia live longer within their own homes and communities.

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14 ibid, p.14
16 ibid
18 Australian Institute of Health and Welfare (2015) website, ‘Hospital Dementia Services Project’ (figures based upon public hospital admissions in NSW in 2006-07)
Alzheimer’s Australia is seeking the support of Commonwealth, state and territory governments to invest into:

• Nationwide and local consumer consultations;
• Comprehensive community education programs that include the Dementia Friends scheme and education tailored to local businesses;
• Resources for communities and local governments, to create dementia-friendly public buildings and spaces, way-finding signage and practices; dementia-friendly design principles for places such as public toilets, parks and gardens, galleries, hotels, public buildings and spaces;
• Dementia-friendly toolkits for local governments, community organisations, sporting and social clubs;
• Road shows to demonstrate to community members how they can implement the concept in their locality, including a mobile dementia-friendly pop up pod to tour the state;
• Support for the establishment of more dementia alliance action groups with key community leaders, retail, events and hospitality organisations who will be challenged to build their own dementia-friendly communities; and
• A multi-media awareness raising promotional campaign.

5.1 AWARENESS RAISING CAMPAIGNS

While dedicated resources are essential to building momentum at a local level and adapting the program to the needs of specific communities, broader campaigns are required to help raise awareness of dementia and shift attitudes. Awareness campaigns will produce social benefits for Australians living with dementia, their carers and support networks; however, such campaigns may also assist in delivering economic benefits to dementia-friendly communities. ‘Hero’ towns may be promoted as leaders in providing a welcoming environment that is good for locals and visitors alike, with the aim of building internal and external recognition of issues affecting those living with dementia. Externally, towns may benefit from the increased recognition of being ‘dementia-friendly’ through higher visitation from older tourists.

5.2 HOW BUSINESSES BECOME DEMENTIA-FRIENDLY

Practical, easy to implement measures a business can undertake include:

• Providing accessible services to people with dementia, including having staff who are able to communicate effectively through an understanding of the condition.
• Support for people living with the disabilities of dementia to continue with paid employment.19
• Working with support groups to develop practical aids to assist people living with dementia such as way-finding signage improvements in shopping centres. In Plymouth in the UK, for example, a local bus company helped design special cards to go with tickets so bus drivers knew what stop a person with dementia would need to get off at.

5.3 HOW OTHER PARTS OF THE COMMUNITY BECOME DEMENTIA-FRIENDLY

• Offer volunteering opportunities for people with dementia.
• Run dedicated local memory cafés for people with dementia and their families.20
• Participate in awareness raising events such as Dementia Awareness Month each September.

19 Alzheimer’s Australia, ‘Creating dementia-friendly communities: A toolkit’
20 ibid
6 MAKING AUSTRALIA A LEADER IN DEVELOPING DEMENTIA-FRIENDLY COMMUNITIES

Although Australia’s work to create more dementia-friendly communities is in the comparatively early stages, pilot sites across the country have already proven their significant potential to change attitudes about dementia through the wide level of support they have attracted from local government, traders, health, emergency services and community groups. This diverse reach of support, backed by local champions, is key to effecting real change and improving the day-to-day lives of people living with dementia and creating stronger, flourishing communities.

A significant opportunity exists to build upon the excellent outcomes of these pilot towns and expand the program further. As the UK experience shows, future opportunities could include expanding the initiative to the retail and hospitality sectors, sports groups and other community touchpoints as funding becomes available.

Alzheimer’s Australia is well-placed to utilise world-first technologies as part of community and business sector education programs. Community leaders, businesses and others may already take advantage of Victoria’s award-winning Virtual Dementia Experience™. This tool uses computer game technology in a dedicated room to immerse the user and powerfully show life through the eyes of a person with dementia as a way of building understanding, empathy and, importantly, knowledge about how even minor changes to the physical environment can make an area more dementia-friendly.

Governments across Australia, businesses, communities and councils, all have a unique opportunity to become more dementia-friendly. In doing so, these communities not only directly support the many people in their areas living with dementia, but create more welcoming, inclusive and enjoyable places to live generally. These communities, with the help of Alzheimer’s Australia, also have the opportunity to benefit socially and economically as they position themselves well for the major demographic shift facing our country as our population ages.

Alzheimer’s Australia is seeking funding to establish more dementia-friendly communities across the nation over the next three years, as we work to position Australia as one of the leaders in understanding and supporting people with dementia.