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**INQUIRY INTO THE DELIVERY OF
OUTCOMES UNDER THE NATIONAL
DISABILITY STRATEGY 2010-2020 TO
BUILD INCLUSIVE AND ACCESSIBLE
COMMUNITIES**

SUBMISSION FROM ALZHEIMERS AUSTRALIA

APRIL 2017

EXECUTIVE SUMMARY

Alzheimer's Australia is pleased to provide a submission to the Inquiry by the Senate Standing Committee on Community Affairs into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities.

Dementia is a progressive disease and it affects everyone differently. The growing numbers of younger people living with dementia will require a shift in how we respond to the needs of younger people living with dementia in the community who receive services under the National Disability Insurance Scheme rather than aged care services. There is an estimated 25,938 people with younger onset dementia in Australia, which is expected to rise to 29,375 people by 2025 and 42,252 people by 2056.

It is therefore crucial that an assessment of outcomes under the National Disability Strategy includes the impact it has had on people living with younger onset dementia. The majority of people with dementia live in the community. Often people feel socially isolated and wish that they had more opportunities to interact with people and to participate in social activities or paid employment. With the support of their community, local businesses and organisations, neighbours, friends and family members, people with living with younger onset dementia can continue to do many of the things they did before they received a diagnosis.

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

Our response to the Inquiry highlights areas of need across planning, design, management, and regulation of important public spaces such as hospitals, and crucial commercial buildings like residential aged care facilities. We highlight the adverse impact that limited social engagement and inclusion has on people living with dementia, their families and cares. We also provide insights from projects that are helping build more dementia friendly and enabling environments across Australia. We share excellent examples of new advances in communication and information systems that can help everyone grasp a better understanding of what living with dementia is like. In discussing innovative new methods, we talk about the ground breaking work that dementia friendly communities across Australia are achieving.

BACKGROUND: DEMENTIA IN AUSTRALIA

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal condition that affects people's abilities and memories.¹ It is surrounded by stigma and misunderstanding,² isolates people living with dementia, their families and carers from social networks,³ and carries significant social and economic consequences.⁴

The care and support of people living with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 410,000 Australians living with dementia and nearly 300,000 people involved in their care; by 2056 there will be over a million people living with dementia.⁵ Younger onset dementia can develop before the age of 65, even as young as 35 years of age and currently, there is an estimated 25,938 people with younger onset dementia in Australia, which is expected to rise to 29,375 people by 2025 and 42,252 people by 2056.⁶

A common misconception is that people diagnosed with dementia are older and live in residential aged care. The reality is that 70% of people with dementia are living in the community at the time of diagnosis and they may be receiving services through the National Disability Insurance Scheme rather than through the aged care system.⁷ Statistics also reveal that dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the fourth leading cause of disability burden overall.⁸

Dementia also has a profound social impact. People with dementia experience stigma and social isolation,⁹ and family carers often find it difficult to balance work, life and caring responsibilities.¹⁰

Many of us will be diagnosed with dementia over the years ahead, or have people we care about faced with a diagnosis. Some of us will be younger than 65 when we develop symptoms or receive a diagnosis, so it is vital that the National Disability Strategy

¹ Mitchell, S et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

² George D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-87.

³ Blay S. and Peluso E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

⁴ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

⁵ The National Centre for Social and Economic Modelling NATSEM (2016). *Economic Cost of Dementia in Australia 2016-2056*.

⁶ NATSEM, *Economic Cost of Dementia*.

⁷ AIHW, *Dementia in Australia*.

⁸ AIHW, *Dementia in Australia*; Access Economics (2009). *Keeping Dementia Front of Mind*.

⁹ Alzheimer's Australia (2014). *Living with Dementia in the Community: Challenges and Opportunities*.

¹⁰ Brooks D., Ross C., Beattie E. (2015). *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. Report for Alzheimer's Australia.

encompasses the needs of people living with younger onset dementia and addresses such themes as accessibility, service quality and community connectedness.

TOWARDS A DEMENTIA FRIENDLY AUSTRALIA

Too often after a diagnosis of dementia, people experience social isolation and discrimination. Friends and even family members may stop visiting or calling because they feel unsure of how to interact with a person who has a cognitive impairment. A 2012 report by the Centre for Health Initiatives at University of Wollongong documented the extent of avoidance and discrimination in the community.¹¹ Half of the respondents of the survey indicated that they thought a person with dementia could not have a meaningful conversation. A third indicated that they found people with dementia to be irritating and approximately one in ten said they actively avoided spending time with people who have dementia. Strikingly, most people surveyed indicated that if they received a diagnosis of dementia they anticipated that they would feel a sense of shame and humiliation. These findings illustrate the avoidance and discrimination that people with dementia face every day.

We also know from talking and listening to people living with dementia that for many people a diagnosis has a significant impact on social relationships, with many people experiencing family and friends no longer wanting to spend time with the person because of their diagnosis. The 2014 National survey of people living with dementia, *Living with Dementia in the community: Challenges and Opportunities*¹² highlighted this dynamic with survey respondents citing the key reasons for this are being afraid of getting lost, not being able to communicate with others and that people seem tense or awkward around them because of their diagnosis.

“Sometimes my social death makes me more sad than the changes to my brain and the loss of my memories. It makes me so angry. I just want to be counted as a person again”.

Lack of understanding of dementia awareness in the community can also lead to unintentional bad treatment of the person with dementia. Retail staff, transport workers and community groups are often unaware of the additional needs of a person with dementia or how to communicate with them. In many communities there are very few opportunities for meaningful social engagement for people with dementia. As a result people with dementia often lead increasingly lonely and isolated lives when with support they could remain actively engaged and connected with the community.

People living with dementia have the same human rights as everyone else: they need to be included in society; they need to be able to live well in the community; they need access to high quality health care; they need access to high quality residential care as their condition progresses, and ultimately they need to be able to die with dignity. They also want to be

¹¹ Phillipson, L., Magee, C., Jones, S. & Skladzien, E. (2012). Correlates of dementia attitudes in a sample of middle-aged Australian adults. *Australasian Journal on Ageing*, 33(3), 158-63. Retrieved from <http://dx.doi.org/10.1111/j.1741-6612.2012.00624.x>

¹² Alzheimer's Australia (2014). *Living with Dementia in the community: Challenges and Opportunities*, National survey of people living with dementia accessed online at https://www.fightdementia.org.au/sites/default/files/DementiaFriendlySurvey_Final_web.pdf

seen for the person they are, not for the condition they have, in all their interactions. Thus, support in the community is essential for people to continue to be involved in the things they enjoyed before they got a diagnosis.

Alzheimer's Australia has been at the forefront of creating a movement to establish dementia friendly communities which we have trialled in specific locations and we are looking to extend to other areas. This is not unique to Australia – dementia friendly community initiatives are working well in the UK, the USA, Taiwan, Indonesia and Japan. In responding to the terms of reference of this Inquiry, we will outline many of the tools and techniques that we have developed that can be more widely adapted to make Australia more dementia friendly.

The National Disability Strategy, NDIS and Dementia

Alzheimer's Australia believes that the NDIS will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception. To date some NDIS participants have received plans that have had positive, life-changing impacts on their lives, however, many others have received insufficient plans that will adversely affect their quality of life and place some at risk of avoidable hospitalisation.

When the NDIS operates as it was originally intended, and participants have the opportunity to exercise 'choice and control' by actively participating in the development of their first NDIS plan, the plan outcomes generally have been positive. However, when the progressing and complex needs of people with neurodegenerative diseases like Younger Onset Dementia (YOD) have been overlooked due to lack of understanding of these diseases (for example, conducting planning sessions over the phone despite communication or cognition challenges, or creating plans that do not address key support needs), the outcomes have been overwhelmingly poor.

People with a progressive neurological diseases like YOD run counter to the 'traditional' trajectory of someone on the NDIS: that is, an ability to enhance independence and re-ablement through a more effective engagement of services. For someone with a neurodegenerative disease, however, care needs inevitably increase over time. NDIS plans for this cohort need to acknowledge this and balance independent goal setting with advance care planning. Individuals with neurological diseases should also have pre-planning education and support to assist them as they consider their future needs that go beyond the first year of their plan.

Consideration of their disease and anticipated progression should also be taken into consideration during planning meetings. People with cognitive or communication impairment require patience and understanding, limited distractions, clear speech, eye contact and non-verbal indicators which are difficult to achieve over the phone. Therefore, when NDIS planning sessions are conducted solely over the phone, many of which, our consumers tell us, have been conducted solely with the person's carer without the participant present (or the reverse), the plan outcomes are less than optimal and the participant (and their supporter) is deprived of choice and control.

To ensure the best outcomes for people with progressive neurodegenerative diseases such as YOD under the NDIS, Alzheimer's Australia has made the following recommendations to the Productivity Commissions Review into NDIS costs:

1. Improved pre-planning support for people with a progressive neurodegenerative disease;
2. NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease; and
3. Mandatory inclusion of coordination of support in all NDIS plans for people living with a progressive neurodegenerative disease.

RESPONSE TO THE TERMS OF REFERENCE

(a) the planning, design, management, and regulation of:

(i) the built and natural environment, including commercial premises, housing, public spaces and amenities

The social impact of dementia needs to be addressed through supporting communities to be more aware of dementia and to provide opportunities for social engagement, volunteering and in some instances paid employment. However, there are there are also several challenges that people living with dementia face in accessing vital health and care services. For the purpose of this Inquiry, we examine the barriers to care faced by people with dementia in accessing appropriate residential aged care services and public hospitals.

Dementia and the Residential Aged Care Sector

Within the aged care sector there is significant work to be done to ensure that we can meet the needs of people with dementia now and as the prevalence increases.

The majority of people within aged care have dementia. We hear that dementia is “core business” of the aged care system – which makes sense given the large numbers of people with dementia in care. But the reality of life within an aged care service for a person with dementia is often very difficult.

In some cases, staff have little training on how to best support a person with dementia. Physical and chemical restraint is used widely. Opportunities for meaningful social and physical engagement are limited. Staff may not be trained on how to communicate effectively with a person with dementia.

“Mother was verbally abused and physically abused by night staff. Staff broke her shoulder and failed to seek medical treatment for over 8 hours despite being asked by my sister if there was something wrong with her shoulder approximately 1 hour after it happened. Local hospital advised that she shouldn't be returned to [the aged care home].”

There is a spectrum of issues around quality in aged care facilities that range from poor quality to criminal negligence and abuse. The quote above, which we received from a consumer, is an extreme example of psychological and physical abuse within aged care.

People living with dementia, their families and carers have indicated there are some basic support that should be provided through the physical and regulated environment:

- To be treated with dignity and seen as a person

- To be supported to have the highest quality of life possible
- To have staff that understand dementia and how to provide appropriate support
- Age-appropriate services and environments
- Access to opportunities for social engagement.

When these issues are raised, often the response is that a move to a more market-based system will drive improvements in quality. Indeed, in many areas markets work and function well to drive improvements. However, relying solely on market-driven service improvement in aged and disability services is ineffective for a number of reasons including:

- Consumers' reluctance to leave a service once they enter due to the disruption of a move
- Lack of competition in rural and remote areas
- The need for urgent access- which limits choice based on availability
- Location preference having a large weight in decisions
- Consumers lack of information about clinical standards and best practice of care.

We need other approaches than just the market to drive quality and improved care outcomes. Essential drivers of improvement of quality include the following areas.

- **Improved Regulation**

In 2015, less than 1% of aged care facilities failed to meet the Accreditation Standards. While it is encouraging that there has been improvement over the last decade, it raises the question of whether the bar is set too low. Given the consumer experience in aged care there needs to be an evaluation of whether 99% of our countries aged care facilities really meet a basic standard of care and support, both in this sector and in disability services.

- **Publically reported quality indicators**

In an aged care context, the National Aged Care Quality Indicator Program started in January 2016 and is voluntary, so aged care homes can choose whether they participate and use these quality indicators or not.

The program is still in early stages with data not yet being publically available. The initial indicators included as part of this program are clinically focused and feedback from consumers indicates that there is a need for publically available indicators that capture consumer experience and quality of life within aged care – as well as other types of services.

In our experience, consumers want to have clear information about the quality of services being offered and the impact of those services on quality of life. There is not a single publically reported measure of quality in aged or disability services and as a result consumer choice is limited.

Alzheimer's Australia has proposed the funding of a consumer-driven Quality in Dementia Care Initiative. Such an initiative would engage consumers and carers to develop and implement consumer and carer based initiatives to monitor and promote the delivery of quality care for people with dementia through aged care services, and through hospitals and other healthcare services. This would include developing checklists and guides for consumers as well as a consumer-audit and feedback program.

- **New models of care**

It is essential that key agencies provide guidance to service providers about new models of care which support people with dementia to live with as high a quality of life as possible. We need to move beyond a medical model of care that focuses on processes and procedures to a psychosocial model that supports people to be engaged and as independent as possible.

The first step of this is for providers and government agencies to listen carefully to the concerns being raised by consumers and develop strategies to address them. What consumers want is a completely different approach to the services they receive – where social wellbeing and quality of life are valued equally to meeting the physical care needs of clients.

Then it is essential that we look at how we can develop regulatory and funding approaches that support and drive new approaches to care that meet the needs of people with dementia, their families and carers. This includes having transparent measurement of quality and standards that include a focus on supporting people with cognitive impairment.

Consumers want to be supported to remain as independent as possible for as long as possible and to continue the activities they enjoy and the relationships that are important to them. People with dementia and their family carers want to be true partners in care and to be heard (and see action) when they provide feedback.

Dementia and Hospitals

People with dementia are major users of hospital services, largely due to the fact that dementia is a chronic health condition, which most commonly affects older people who are more likely to have other chronic conditions. One in every four people with dementia requires hospital services each year, which is twice the rate for people of the same age who do not have dementia. 20% of people over the age of 70 in hospital have dementia.¹³

People with dementia also generally have a longer length of stay within a hospital than other patients, leading to greater costs to the health system. There are several reasons that people with dementia may end up in hospital unnecessarily, including limited availability of appropriate care in an alternative setting (particularly respite care), no or limited family support, lack of availability of medical services in the home, or a need for care whilst awaiting admission to another care facility. The cost of preventing hospital admissions is estimated to be \$888 per day in savings.¹⁴

As the prevalence of dementia increases, it is critical that all hospitals and other health services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business.

The evidence on dementia care in hospitals suggests that despite the high use- people with dementia often do not receive appropriate care.

Research by the AIHW has shown:

¹³ Australian Institute of Health and Welfare (2013). *Dementia care in hospitals: costs and strategies*.

¹⁴ AIHW, *Dementia care in hospitals*.

- Poor identification and reporting of dementia with approximately 50% of people with dementia not having their diagnosis recorded. This lack of identification can increase the risk that the person with dementia will not be provided with appropriate care.
- Longer stays and have higher associated costs of care for people with dementia compared to people of similar ages with similar health conditions.
- Worse clinical outcomes than other patients, including increased risk of adverse events and preventable complications, and are more likely to die in hospital than other patients.

'Nursing staff assume that the dementia patient can convey their wishes and ask for assistance (for example, 'Just ring the bell if you need anything'). But the person with dementia may not remember there is a bell and may not be able to indicate what their needs are.'

'The rehab staff said Mum wasn't motivated. I told them that was because she didn't have her slippers. She wouldn't walk in bare feet at home without her slippers so no way would she walk on a hospital floor without them! As soon as she got the slippers, she did all her exercises.'

If staff make the effort to understand what the needs of the person with dementia are, care can be delivered far more effectively, as the above quote illustrates. Involving the carer and asking their advice about the patient and how best to care for them, is vital.

The quote below highlights the issue of chemical and physical restraint in hospitals. The need for restraint can usually be avoided by taking simple measures to understand and meet the person's needs.

'On his third night at the hospital, [my husband] tried to climb over the bed-rails to follow us when we left. Someone on duty made the judgement to give him five times his dose of the antipsychotic, Risperidone, to 'quieten him down'. He was rendered unconscious for the next five days...A second admission... He was nursed postoperatively with both wrists and ankles tied to the bed-rails for 48 hours, so he would not 'pull his tubes out'. This occurred in the absence of consultation with myself and our family.'

An expert symposium held by Alzheimer's Australia in 2014 identified several issues that need to be addressed to improve care for people with dementia in the hospital system:

- Better identification of cognitive impairment in hospitals – this involves identifying and managing dementia at hospital admission, and planning for discharge from the outset.
- Increased training for all hospital staff including how to communicate with a person with dementia, how to respond to the behavioural and psychological symptoms of dementia, and alternatives to antipsychotic medications and sedatives, such as psychosocial interventions.

- More extensive and systematic involvement of carers as partners in the care and support of patients.
- Creation of appropriate physical environments to reduce confusion and distress and help orient people with dementia.

The Australian Commission on Safety and Quality in health care has provided leadership and vision in improving hospital care at the systems level for people with dementia. They have implemented the “Caring for Cognitive Impairment Campaign” which promotes awareness about the need for appropriate care and support for people with dementia in the hospital system. It provides resources which outline *Actions for Health Service Managers*, *Actions for Clinicians* and *Actions for Consumers* to promote better care. More than 130 hospitals have indicated a commitment to taking action to improve care for people with dementia as part of this campaign.

The Commission has also embedded the need for better identification and care for people with cognitive impairment throughout Version 2 of the National Safety and Quality Health Service Standards. A specific delirium clinical standard has also been developed by the Commission which identifies the key steps for preventing and providing appropriate treatment for people with dementia.

This combined approach of incorporating dementia into the standards while also providing support for increasing awareness and steps for quality improvement has the potential to transform the hospital system in terms of the care it provides for people with dementia.

There are also some very positive “on-the-ground” initiatives to improve dementia care in hospitals.

- **The Dementia Care in Hospitals Projects (VIC)**

The Dementia Care in Hospitals Project is a national project based on a model of care developed by Ballarat Health Services in conjunction with Alzheimer’s Australia and people with dementia and their families. This approach is based on staff education and cultural change linked with an over-bed alert – a visual Cognitive Impairment Identifier – which alerts staff to memory and thinking difficulties.

This approach has been shown to improve staff and carer satisfaction with the care provided to people with dementia in acute care facilities. It has been implemented in over 20 hospitals across Victoria, and is now being rolled out and further evaluated in four states across Australia as part of a government funded initiative.

- **Care of Confused Hospitalised Older Persons (CHOPs) program (NSW)**

Another example of a positive local initiative to improve hospital care is the Care of Confused Hospitalised Older Persons (CHOPs) program. The aim of this program is to improve the experiences and outcomes of confused older people in hospital. It is a collaboration between the NSW Agency for Clinical Innovation (ACI) and the NHMRC Cognitive Decline Partnership Centre (CDPC).

The specific objectives of CHOPs are to:

- Design and prioritise principles for best practice care for older confused people in hospital;
- Tailor implementation to the needs of the older person, carers and families and the hospital teams; and
- Share achievements, innovation and knowledge and embed systems into practice to sustain and spread improvements in the care of older confused people in hospital.

There are 7 key principles of the program:

- Undertake cognitive screening
 - Delirium risk identification and prevention
 - Assessment of older people with confusion
 - Management of older people with confusion
 - Effective communication to enhance care
 - Staff education
 - Supportive care environment.
-
- **TOP 5 Program (NSW)**

Another example of a positive initiative in the hospital system is the TOP 5 model developed in NSW, which recognises the value of carers in informing the provision of appropriate health care for a person with dementia or other cognitive impairment.

This simple initiative aims to encourage health professionals to engage with carers, to better personalise care. Carers are asked to provide the top 5 strategies or tips which will best support the person with dementia. The information is documented on a TOP 5 form made available to every member of the care team.

Initial evaluation of this initiative has shown great promise including ease of uptake, high acceptability to staff and carers, a decrease in the need for intensive staffing, a reduction in falls, and a reduction in the use of anti-psychotic medication.

Given the work happening in the acute care sector, Alzheimer's Australia is optimistic that we are moving towards a health system that will be better equipped to support the increasing numbers of people with dementia.

(ii) transport services and infrastructure

Transport Services

Access to appropriate transport options is essential to ongoing involvement in the community for people with dementia. People with dementia will need to give up their drivers licence at some point following diagnosis. Often this creates a crisis as it means a significant loss of independence and control. With access to appropriate community transport people can continue to engage in activities they were involved in before losing their licence.

People with dementia commented extensively on this issue:

“As I no longer have a driving licence I would like to have more public transport available or more transport from services”.

“I am now wheelchair bound. I need to be accompanied and use access cabs which are not freely available during the week.”

“I can’t drive, shops are too far, family works and has no time. My kids take me to church I enjoy that.”

“My wife and I no longer drive and live on a farm in a small community. There is no public transport so rely on family and friends to attend to our shopping.”

Ensuring that people with dementia have appropriate and supported access to public transportation services should therefore be a crucial element of assessing the Disability strategy.

Infrastructure

Consumers have told Alzheimer’s Australia that that changes to community physical environments would improve their ability to access and interact within their community. For example, minimising noise where possible, less reflective surfaces such as glass and better maps, signage and directional cues.

One consumer has described in detail changes to the community environment that would greatly improve their experience:

“Attention paid to reducing hard surfaces, minimising noise, muzak and use of microphones to advertise wares, providing clues as to directions, painting doors to toilets in different colour, minimising reflective surfaces in toilets, providing maps of shopping centres etc.”

Alzheimer’s Australia in collaboration with University of Wollongong has created a dementia friendly audit tool for public spaces, which will assist organisations and communities to identify ways to improve the physical environment to make it more dementia friendly. This tool is available online through the Dementia Enabling Environments Project website.

Dementia Enabling Environments Project (WA)

The Dementia Enabling Environment Project (DEEP) provides for the increased demand for enabling environments for people living with dementia. The DEEP project was led by Alzheimer’s Australia WA in partnership with University of Wollongong. This national project is focussed on translating research into practice in the area of enabling environments for people with dementia. This is an Australian first project that translates enabling environments research into practice and focuses on architecture, interior design and gardens. The project team assist architects, designers, landscapers, aged care staff, families and those with dementia to refurbish or build future care environments and support families to adapt their homes by identifying key environmental changes.

The DEEP team provides consumers with a wide range of practical, inexpensive and useful ideas, examples and recommendations as well as resources to make the necessary changes and evaluate the outcomes.

The project has also been successful in introducing cognitive impairment design principles into tertiary architecture programs run by several Australian universities. It has also worked to achieve dementia-enabling regulation through membership on two Australian Standards review panels and helped provide evidence of how initiatives can cross inter-sectoral barriers and engage diverse professional groups.

(iii) communication and information systems, including Australian electronic media and the emerging Internet of things

Alzheimer's Australia has been driving innovative new approaches that try and improve the quality of care for people with Dementia. Some of these are exciting new technologies that can help enable understanding of dementia.

Virtual Dementia Experience (VDE)

An example of how innovative technology can influence practice and policy is the Virtual Dementia Experience, developed by Alzheimer's Australia Victoria. The aim is to help care professionals understand how a person with dementia experiences the world, and what environmental aspects are friendly or hostile to the person with dementia.

Launched in October 2013, the Virtual Dementia Experience is an immersive, interactive virtual reality experience that invades the senses and takes people into the world of a person living with dementia, simulating thoughts, fears, and challenges. The simulation uses game technology and was created in collaboration with Melbourne game developers Opaque Multimedia. It has been recognised by a number of state and national awards, and is a really innovative use of technology to improve care and outcomes for people with dementia.

Educational Dementia Immersive Experience

Another innovation in technology is the just released app EDIE, the next generation in the use of serious games technology developed by Alzheimer's Australia Vic. The app, EDIE, (Educational Dementia Immersive Experience, pronounced Eddie), is used exclusively with Google Cardboard and aims to build empathy in the user for people living with dementia – as it is designed to let people into the world of the person living with dementia. EDIE provides the user with a 360-degree immersive experience that enables them to see first-hand the challenges faced by people with dementia.

Imagine being able to take a person with dementia out of their everyday experience and into a virtual environment through which they will experience awe, wonder, amazement and joy.

Virtual Forest

The Virtual Forest project is another foray by Alzheimer's Australia Vic into virtual support for people with dementia. The project uses a sensory therapy application designed to improve the quality of life of people living with dementia through the use of video game technology.

It utilises cutting-edge technology, which aims to turn a living room or lounge in an aged care home into an enchanted space that both stimulates the senses and engages through interactivity. The virtual environment is being designed from the ground up specifically for people with dementia and will provide a beautiful, calming and highly interactive experience.

(b) potential barriers to progress or innovation and how these might be addressed

As highlighted above, Alzheimer's Australia believes that there needs to be a more strategic and holistic response towards making Australia a more dementia-friendly country. Being dementia friendly however not just about creating separate groups or activities for people living with dementia. It is about ensuring existing activities that people already enjoy to still be accessible and welcoming for people with dementia regardless of a person's dementia diagnosis. A dementia-friendly community supports people living with dementia to live a high quality of life with meaning, purpose and value. It supports being able to continue the activities and interests of the person, in the same way the rest of the community does, regardless of having a diagnosis of dementia. With 70% of people with dementia residing in the community it is imperative from both a social and economic perspective that people with dementia are supported to live well with dementia in the community.

We surveyed more than 1,000 Australians 2015, and nearly two thirds of the people we surveyed admitted to knowing very little about dementia, while more than half said they would rather not even think about dementia. This level of denial indicates that the fear and stigma surrounding dementia remain very strong in our community. In fact, 25% of the people in our survey said that they find people with dementia frightening.

People with dementia, like all other people, deserve to be able to live a life with meaning and purpose. Try to imagine what it would be like if you or someone you care about had dementia, and having the condition meant people avoided spending time with you, and were even afraid of you. This is the reality people with dementia are faced with every day in Australia. People are often afraid of what they don't understand. We need to raise awareness and break down the stigma and misconceptions that go with a dementia diagnosis, so people living with the condition are treated with dignity and understanding.

Over the past 10 years, a global social movement to create Dementia Friendly Communities has started to change how we view dementia, and is helping us to respond more positively to people living with the condition.

CASE STUDY: Dementia Friendly Dance Classes in Bribie Island

By listening to people living with dementia in the community, the local dementia alliance on Bribie Island identified that there was a lack of socially engaging activities within the community. As a result, the local dance instructor decided to hold dance classes that would be inclusive of people living with dementia. A suitable venue was sourced and the instructor centred the class on the abilities of the participants rather than following her standard class structure. This ensured that all participants could enjoy the lesson and not feel excluded.

As one carer commented about her husband with dementia,

"The dance class brought back youth activities to him with caring and achievement, and it made him feel good. He has been engaging positively ever since."

This example comes from one of six sites piloting the Dementia Friendly Communities approach in Australia, an initiative led by Alzheimer's Australia.

Some positive early outcomes we've already seen from our Dementia Friendly Communities work in Australia include:

- Meaningful social engagement for people with dementia, through memory cafes, choirs, walking groups, sporting clubs, and other social groups that are welcoming of people with dementia.
- Volunteering buddy programs have been created across Australia where people living with dementia are involved in developing a local volunteering program in partnership with local organisations.
- Toolkits of dementia friendly resources has been developed for businesses and members of the community, as well as local government.
- Environmental audit tools have been developed to outline best practice design and provide information to assist architects, designers, landscapers, and aged care staff to create dementia enabling environments.
- The University of Wollongong has also developed an interactive mapping tool called *Ourplace*, to allow users to map places and spaces that they feel could be improved to enable people with dementia to better access care and support.
- The Alzheimer's Australia, University of Wollongong and Kiama Municipal Council Dementia Friendly Communities project has resulted in being the only DFC initiative globally to be recognised for excellence by the World Health organisation.

Experience from these pilots suggests that there is significant community and business goodwill that can be leveraged to better support people with dementia. Very small investments have led to significant achievements, but communities need to be adequately supported to achieve ongoing results over a sustained period. Attitudinal and social change takes a longitudinal approach and strategies such as the National Disability Strategy should reflect this.

(c) the impact of restricted access for people with disability on inclusion and participation in economic, cultural, social, civil and political life

Dementia has profound social implications for both people with dementia and their family and carers. Often after a diagnosis of dementia, people experience social isolation and discrimination. Friends and even family members may stop visiting or calling because they feel unsure of how to interact with a person who has a cognitive impairment. Many Australians have little understanding of dementia and are unsure of how best to respond to people who are living with the disease.

As stated in previous sections above, an Australian National Population survey in 2014 found that:

- 44% of people believed that people diagnosed with dementia are discriminated against or treated unfairly; and
- 22% indicated they would feel uncomfortable spending time with someone who had dementia.

As a result, people living with dementia, their families and carers often lead increasingly lonely and isolated lives, when with support, they can remain actively engaged and connected with the community. This isolation can lead to mental health concerns including anxiety and depression and can exacerbate the symptoms associated with dementia.

People with dementia who are isolated often require residential care services earlier. Carers who experience social isolation can have difficulties maintaining their caring role and experience negative impacts on their mental and physical health.

In 2015, Alzheimer's Australia conducted a national survey to examine the experience of loneliness for people with dementia and their carers, compared to the experiences of the general public.¹⁵

We then used these results to validate our awareness raising campaign during dementia awareness month by trying to highlight to the general public, via traditional and social media, the profound issue of social isolation and loneliness, for people living with dementia and their carers.

- 1,500 people participated in the survey;
- 62 responses came from people with dementia;
- 745 came from carers; and
- 698 were from the general public.

The results showed people with dementia are almost twice as likely to have high rates of loneliness compared to the general public.

The survey also found that people with dementia report significantly fewer relationships than carers, who in turn have significantly fewer relationships than the general public. This was mainly due to friendships falling away, often leading to the experience of being socially isolated. People with dementia are more than twice as likely not to see any friends when compared with carers and the general public, and more than three times as likely not to have a confidant or a friend to call on for help when compared with the general public.

These results only reinforce the reason why dementia-friendly communities is, and needs to remain, a priority, and why disability, wellbeing and other community-based strategies need to reflect the importance of inclusion and participation.

ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.¹⁶

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care.¹⁷ Our organisation advocates for the needs of people living with all types of dementia, and for

¹⁵ Ipsos research for Alzheimer's Australia (2015). *Perceptions and Understandings of Dementia*.

¹⁶ Australian Bureau of Statistics (2015). *Causes of Death, Australia, 2013*: Cat no. 3303.0.

¹⁷ AIHW, *Dementia in Australia*.

their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.