# ALZHEIMER'S AUSTRALIA WA Dementia Friendly Communities Project: Creating a Dementia Friendly WA

# A REPORT ON THE STATE-WIDE CONSULTATION ON THE EXPERIENCE OF LIVING WITH DEMENTIA IN WA



**DECEMBER 2014 – MARCH 2015** 

SPONSORED BY THE DEPARTMENT OF LOCAL GOVERNMENT AND COMMUNITIES SOCIAL INNOVATION GRANTS PROGRAM





Sponsored by the Social Innovation Grants Program

# **Alzheimer's Australia WA**

#### **Our Vision**

A society committed to preventing dementia, while valuing and supporting people who live with it.

#### **Our Purpose**

To advance the interests of people living with dementia through advocacy, education, support and research.

#### **Our Philosophy**

Dementia is a human experience rather than just a biological condition. We therefore offer a holistic approach in our care that respects the individuality of people living with dementia.

#### **Our Values**

We strive to be a professional, empowering, compassionate and accountable organisation of integrity that empathises, collaborates, innovates and values the well-being of all.

As such, we will: understand the unique needs of people with dementia, recognise people as our greatest strength, invest in partnerships, treat people with respect and dignity, encourage innovation and creativity and be transparent and accountable at all times.

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# **1. EXECUTIVE SUMMARY**

Alzheimer's Australia WA (AAWA) is focussed on a society committed to preventing dementia, while valuing and supporting people who live with dementia. Whilst there have been improvements, there is a long way to go, partly because of a lack of detailed knowledge about the experiences of those living with dementia.

The Government of Western Australia has funded this project to be future focussed. It aims to provide the in depth views of the people who are living with dementia. The views of these people count and understanding their experiences living in the community is a first stage on the road to a truly dementia friendly Western Australia.

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

The consultation explored three key areas; positive experiences, frustrations and barriers and what a dementia friendly community would look like or include. By engaging those living with dementia, their families, carers and local government representatives, extensive understanding has been developed.

Eight key outcomes and suggested future actions for creating a dementia friendly community have been identified:

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

These findings reinforce that awareness of and strategies to support people with dementia are at a very early stage of development. Much work needs to be done on understanding and developing a successful set of community based strategies.

Creating a dementia friendly community is challenging. This study of the drivers of a dementia friendly community is a good first step. It represents one of the first attempts made to engage people living with dementia on their needs. While there is still work to be done to create a truly dementia friendly WA, the findings influencing this report have established aspirations for a future focused approach.

# 2. BACKGROUND

Alzheimer's Australia WA received a social innovation grant from the Department of Local Government and Communities to implement the Dementia Friendly Communities Project. This two year project is developing a range of initiatives to create a Dementia Friendly Community approach across WA. A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value. Each dementia-friendly community will be different from the next but all will increase community awareness about dementia and reduce stigma, will support people to continue involvement in activities they enjoy and reduce social isolation. Improving both the community's physical and social environment will make it easier for people with dementia to remain engaged in their community.

To know exactly what is needed, AAWA hosted community consultations and invited people living with dementia and their carers/support persons with the purpose of understanding what it is like to live with dementia in their community. Thirteen workshops were held from December 2014 to March 2015.

This initiative explored the experiences of people living with dementia based on the findings from 13 workshops carried out across the state of WA. People living with dementia were invited to participate in these shared group discussion workshops to identify possible solutions and needs for the development of dementia-friendly communities.

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

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

"I hope these meetings help to bring more awareness and acceptance of Alzheimer's to the wider community." - Quote from workshop participant.

# 2.1. Project

# Living with Dementia Consultations

Alzheimer's Australia WA engaged Creating Communities to assist with, and support, the Living with Dementia Workshop series through establishing a Marketing and Communications Plan (refer to Appendix 5.3), workshop conceptualisation, preparation and logistical organisation, feedback on delivery, and preparing the final Consultation Report.

This series of workshops focused on how to create dementia-friendly communities (DFC) and provided the opportunity for increasing awareness, advocacy and understanding of what it is like to live with dementia in Western Australia's current context.

The workshops also provided the forum for attendees to provide feedback, voice their opinions and help make a difference for people living with dementia in WA.

"It's [dementia] only going to get bigger." – Quote from workshop participant.

# Report

This report examines the findings from the workshop series in two ways: firstly, an overall perspective that covers all responses and identifies the key themes and opportunities. Secondly, it reports findings based on the location of each workshop, providing links to the local government and service providers, thereby allowing a more targeted analysis of the experiences of those people living with/caring for someone with dementia in each location.

This document is intended to communicate the grassroots experience of those who: are living with a diagnosis of dementia; care for someone with dementia; or, have been affected by dementia. Through communicating these messages, the contents aim to increase the conversation and action around the concept of Dementia-Friendly Communities, encourage the government to prioritise the implementation of dementia friendly aspects in their strategic planning process and contribute to the planning and policy-making of Alzheimer's Australia WA

The target audience for this report includes the State Government (particularly the Department of Local Government and Communities), Local Government (particularly Community Inclusion Specialists), consumers, workshop participants and service providers.

"People need to be a lot more understanding. How you fare depends on who you are dealing with." – Quote from workshop participant.

# 2.2. Recommendations

Dementia Friendly Communities - Community Consultation Recommendations:

Outcomes for a Dementia Friendly WA	Consumer Recommendations	Recommended Action
Reducing stigma through improved awareness and understanding of dementia in the general community	<ul> <li>Increased awareness in schools</li> <li>Greater awareness across the community of the impact of living with dementia</li> <li>Raised profile of dementia through utilising famous people and a campaign approach</li> </ul>	<ul> <li>Establish a schools dementia awareness program across WA to inform and educate students</li> <li>Comprehensive WA community awareness campaign to de-stigmatise dementia and increase understanding</li> <li>Raise profile of dementia awareness month (September)</li> <li>Recruitment of high profile dementia ambassadors to raise awareness</li> </ul>
Increased knowledge of dementia in GP's hospitals and primary health services	<ul> <li>Better awareness and support from GP's</li> <li>Easier and quicker diagnosis</li> <li>Increased dementia understanding and skills from allied health professionals</li> <li>Development of a consistent dementia friendly hospital approach</li> </ul>	<ul> <li>GP training program to aid early detection and referral to support services</li> <li>Improved accessibility to specialists to aid diagnosis</li> <li>Dementia specialist training programs to be available for allied health staff e.g. dentists, optometrists, podiatrists etc.</li> <li>Hospitals to adopt dementia enabling environment design</li> <li>Increased dementia training for hospital staff</li> <li>Family support packs available on hospital wards</li> <li>Adoption of dementia champions in each hospital</li> </ul>
Development of built environments that enable people living with dementia	<ul> <li>Dementia design principles to be included in planning and development process</li> <li>Improved dementia accessibility to public buildings e.g. shopping centres, library, museums etc.</li> <li>Address urban design considerations for people living with dementia</li> </ul>	<ul> <li>Improved dementia appropriate signage to aid wayfinding</li> <li>Incorporation of dementia design principles in design process</li> <li>Inclusion of dementia specialist knowledge on planning and advisory groups</li> <li>Review of existing accessibility of buildings for people with dementia</li> <li>Consideration of the needs of people with dementia in local government urban planning</li> </ul>

Outcomes for a Dementia Friendly WA	Consumer Recommendations	Recommended Action
Increased awareness of customers needs with dementia in businesses and services	<ul> <li>Knowledgeable and aware business staff to recognise the needs of customers with dementia</li> <li>Consumers to be able to identify dementia friendly businesses and services</li> </ul>	<ul> <li>Incorporation of dementia specific training programs for service staff</li> <li>Development of resources and support for businesses and services to become dementia friendly</li> <li>Development of a symbol for people living with dementia to recognise dementia friendly businesses</li> </ul>
Increased support and information for families/carers	<ul> <li>Improved access to training and information for families throughout WA</li> <li>Development of a one stop shop for family support, information and education</li> </ul>	<ul> <li>Expansion of existing dementia specific training and information services</li> <li>Improved marketing to help families become aware of what is available</li> <li>Expansion of AAWA information and resource centres</li> <li>Family information packs to be available at pharmacies, medical surgeries etc.</li> </ul>
Improved access to social clubs and activities for people living with dementia	<ul> <li>Broader services that enable the person and carer/family to socialise together</li> <li>Existing groups and clubs to be inclusive of people living with dementia e.g. golf clubs, Men's Sheds, gyms etc.</li> </ul>	<ul> <li>Dementia training and information programs for community social clubs</li> <li>Dementia inclusion planning by local governments</li> <li>Support to museums, galleries etc. to develop dementia specific services and accessibility</li> </ul>
Increased availability of person centred care services	<ul> <li>Increased access to dementia specialist day and overnight respite services</li> <li>Equality and consistency in the provision of person centred dementia care in residential facilities</li> </ul>	<ul> <li>Expansion of innovative flexible dementia specific respite service options</li> <li>Development of local community cottage respite in rural communities</li> <li>Increased training for aged and heath care staff on person centred care</li> <li>Recognition of need for younger onset dementia specific services</li> </ul>

Outcomes for a Dementia Friendly WA	Consumer Recommendations	Recommended Action
Improved transport support for people with dementia	<ul> <li>Access to training for staff to recognise the needs of passengers with dementia</li> </ul>	<ul> <li>Dementia awareness and understanding training to be available for public transport and taxi staff</li> </ul>
	<ul> <li>Better awareness of current and available services for people living</li> </ul>	<ul> <li>Public transport design to be dementia friendly and accessible</li> </ul>
	<ul> <li>with dementia</li> <li>Improved facilities/modes of transport for people living with dementia e.g. frequency and flexibility of services across WA</li> </ul>	<ul> <li>Transport wayfinding and information to be supportive of people with dementia</li> <li>Regional needs for public transport services to be considered</li> <li>Recognition of disabled parking needs for people with cognitive impairment</li> </ul>

# 3. METHODOLOGY

# 3.1. Philosophy of Workshop Series

Alzheimer's Australia WA understands the effects that dementia has on the individual, family, friends and the broader community. It is important that those living with dementia or caring for someone with dementia are supported and a degree of sensitivity is maintained; therefore, the concept of the Community Café was developed. The philosophy of the workshop series was to create a relaxed, informal atmosphere. Participants were invited to a morning tea that allowed for socialising and sharing of experiences as well as the consultation regarding dementia-friendly communities.

*"Very enjoyable, well-organised and social. There was a relaxed, yet professional feel to the event."* – Quote from workshop participant.



The workshop in Geraldton saw 17 attendees discussing how to create dementia-friendly communities.

# **3.2. Format of Workshops**

Creating Communities worked collaboratively with Alzheimer's Australia WA to produce a detailed workshop plan. Alzheimer's Australia WA staff then conducted the workshops. Please refer to Appendix 5.1 for the Living with Dementia Community Café Format and Agenda that was used at each of the 13 workshops.

The workshop series was centred on three key questions:

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

This report provides a summary and analysis of the findings from the information gathered through the series of workshops.



Consumers participating in the Floreat Community Café workshop.

# 3.3. Examples used at each workshop

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

The examples given for question 1 (positive experiences) and question 2 (barriers and frustrations) remained the same for every workshop. The examples regarding a dementia-friendly community were different for each workshop, and specific to the area within which the workshop was held. This was to encourage participants to think in their local context when generating possible changes needed to make their community dementia-friendly. It is important to acknowledge the example given alongside each question as it may have influenced or guided the discussion and participants' responses. Please see below the examples used:

# **Question 1: Positive experiences - Example**

Gym experience – a lady was no longer able to drive to gym, so walked. The gym was notified and if she took longer than 30 minutes, they would look out for her. When she was no longer confident in walking to gym, she was picked up and driven there by a gym staff member. Staff kept an eye on her during the workout and then dropped her home.

### **Question 2: Frustrations/barriers - Example**

Casino experience – a lady got stuck on the black reflective flooring as she could see the ceiling on the floor and her spatial perception was altered and she couldn't move. Her husband had to ask a staff member to obtain a wheelchair to take her off the reflective flooring. Due to that section of flooring, the couple were not able to access other parts of the Casino complex.

#### Question 3: Changes to make a dementia-friendly community - Example

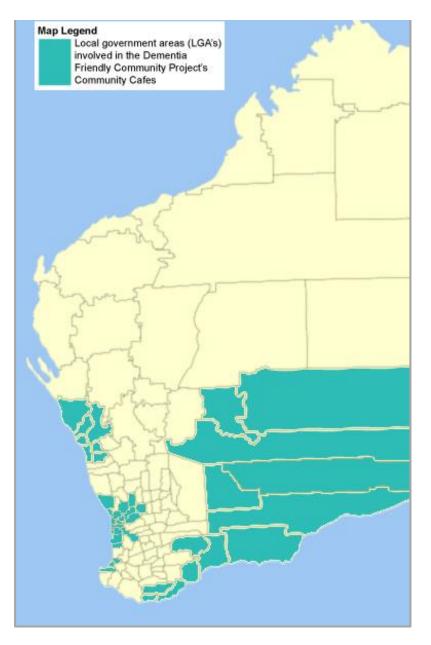
At each workshop, broad examples of community development and awareness, and enabling environments were provided. Facilitators endeavoured to vary these examples slightly for each location to be specific to the area, while still using similar terminology.

# 3.4. Detail on the Workshops

Local government representatives from each of the workshop locations were invited to be involved in the planning, workshop logistics and attend the workshop, the response and support differed between locations. There were some overlaps between different local government authorities (LGAs) being involved in workshop locations; please see map below highlighting the areas and the participating LGAs involved with the workshop series.

Forty-eight LGAs helped with promoting the Workshop series and 26 of those had a representative present.

Please refer to Appendix 5.2 for details on the thirteen workshops.



Map 1: Participating LGAs involved with the Workshop Series

# 4. SUMMARY OF FINDINGS

This section provides a summary of findings across all 13 workshops. It is separated according to the three core discussion topics: positive experiences, frustrations and barriers, and suggested changes. As comments were broad in nature, to help highlight the most common points, responses have been grouped by theme and counted, then ranked according to frequency. Counting in the findings section represents data from a group of attendees (seated on the same table) not an individual attendee. For a theme to be included in this section of the report, it must have been mentioned at least twice throughout the series of workshops.

For detailed findings by individual location, please see Section 5.

# 4.1. Positive experiences

The following section summarises responses to the question: "In regards to living with dementia in your community, what has been a positive experience for you and your family?" The vast majority of positive experiences reported related to engaging with services, community or social groups.

Responses have been themed into the following six high-level categories; services community, family and social, facilities, business and individual care.

All comments have been themed and organised under the six categories and are listed in order of their prevalence during the community workshops.

# 4.1.1. Services

Care centres, such as respite care and day care, were the most commonly-mentioned services when it came to positive experiences. Such services operate across WA and many were mentioned by name as part of the discussions.

# Services providing for the needs of a person with dementia

Respite / care centre / Day care (e.g. Highcare, Morrisey, Bethanie, Swan, HACC, Melville, Addie Mills, Hawthorn House, Killara) Hospitals / hospital staff / hospital mental health service GP / Doctor Services focused on inclusion Specialist Support) Home care Library providing resources and information

# Services providing support for person with dementia

Meals on Wheels / delivery services SilverChain Carers Local library / library staff Men's Shed Police Taxi service (UK) / Share and Care driver Fitness and exercise services / local gym

# 4.1.2. Community and community groups

Workshop attendees referred to a wealth of positive experiences in relation to the broader community and community groups. Specifically, the community were often mentioned as being helpful, caring and supportive, and having a positive attitude, awareness or displaying patience. Positive experiences were also mentioned with regard to neighbours and support from neighbours.

Amongst a variety of community groups, men's sheds were found to be a strong source of positive experiences.

#### **General Community Care and Support**

Community is helpful / caring / supportive Community attitude / awareness / patience Neighbours / supportive neighbourhood Youth approach / school visits Community knowledgeable Education and information

#### **Community Groups**

Men's Shed Sporting clubs (e.g. bike, bowling) Choir Volunteering at community groups Walking Group Church / church groups Explorer club Gardening Club / Village vegetable patch

# 4.1.3. Family and Social

Support from family and friends is clearly an important and positive part of life for people with dementia and their carers. This came through strongly in the discussions.

### Family, friendships and other social support

Family support Social friendships Friendship groups Sharing experiences / knowledge Social groups Having a laugh with friend

# 4.1.4. Facilities

Workshop attendees related positive experiences across a broad range of facilities. Public parks, swimming and other sports and recreational facilities were among the most popular of the amenities mentioned.

### Facilities

Public parks Swimming / water therapy Sport / recreational facilities (general) Friendly community facilities Public transport Training for staff at facilities Short-break accommodation and visits

# 4.1.5. Businesses

Many workshop attendees had positive experiences interacting with businesses, particularly with regard to businesses (and their staff) displaying awareness through taking a caring approach towards the person with dementia. These comments were generally in relation to day-to-day shopping experiences such as visiting the supermarket, local café or chemist.

#### Businesses

Business awareness (e.g. understanding, respectful, catering for individual) Business caring/looking out for person with dementia

# 4.1.6. Individual

Positive experiences of individuals were commented on under two key themes - enjoyable solo activities (such as creating art or listening to music) and maintaining & enjoying independence, including involvement in activities they enjoy.

# Individual

Enjoyable activities (e.g. art, games, quiz, music, walks, animals) Maintaining & enjoying independence

# 4.2. Frustrations and barriers

The second focus area for discussion in the community workshops was frustrations and barriers. Participants were asked to respond to the following question: "In regards to living with dementia in your community, what has been a frustration or barrier for you and your family?"

Five high-level categories have been used to group the responses: physical environment, travel and amenities, attitudes, understanding and awareness, doctors, medical and government, services and emotions and personal challenges.

All comments have been themed and organised under these five categories. Again, comments are ordered according to the prevalence during the community workshops. Interestingly, many of the areas where positive experiences were mentioned also came up in the frustrations and barriers.

# 4.2.1. Physical environment, travel and amenities

The physical environment and moving around in this environment offers a broad range of challenges for a person with dementia and their carer. Commonly mentioned frustrations include a lack of signage or navigation tools, loud noises, flooring, a lack of walker or wheelchair access, and a general difficulty going out and travelling.

# **Physical Environment / Access**

Loud noises (e.g. music, announcements) Flooring (e.g. carpet, footpaths) Lack of walker / wheelchair access Windows / glass / mirrors Steps / kerbing General physical environment not fit for those with a disability Lack of benches / seating Design not sympathetic to access (i.e. – loose mats/floors/surface, toilet entry) Lack of footpaths on minor roads Lack of lighting

# **Transport and travel**

Difficulty of going on outings Travel Lack of drivers / transport services / must use public transport

# Amenities

Lack of signage / navigation tools (e.g. toilets, public transport, signage too small, inappropriate or non-existent) Shopping - access / layout / checkouts Lack of toilets

# 4.2.2. Attitudes, understanding and awareness

Although attitudes, understanding and awareness were described as positive experiences, it is clear that many individuals have also had negative experiences in this area. In particular a lack of understanding or patience was mentioned numerous times. A lack of family support was also discussed as well as general negative attitudes.

# Lack of understanding attitudes/awareness/education

Lack of understanding / patience Lack of family support (e.g. family may be in denial) Negative attitudes Lack of communication Lack of knowledge / education Disrespectful / judgemental Social isolation Negative attitude Lack of education and training

# 4.2.3. Doctors, medical and government

Workshop attendees mentioned negative experiences across a range of medical services and government interactions. Specifically a lack of care and understanding from Centrelink was highlighted, along with lack of support and understanding from General Practitioners (GPs).

#### **Medical services**

GP - does not understand / lack of support / reluctant
Lack of awareness and understanding of patient limitations
Lack of information from GP
Lack of understanding
Lack of education about high care facilities and the transition in to such a facility
Doctor not recognising problem / gaps in diagnosis
Lack of awareness in Hospital staff
Hospital appointment - always needing to travel
Lack of collaboration / coordination

# Government

Lack of care and understanding from Centrelink Lack of funding / financial support

# Communication

General lack of communication between service providers, the GP and the carer Comprehension of questions

# 4.2.4. Services

Despite being described in a positive light on numerous occasions, respite care was also found to be a source of frustration for workshop attendees. Lack of services (including services for carers) was also mentioned a number of times.

### Services

Lack of respite care Lack of services (or knowledge of these services) Lack of services / support for carers Lack of activities and support groups No one stop shop to find information Lack of training for carers

# 4.2.5. Emotions and personal challenges

Living with a diagnosis of dementia can clearly be difficult on a personal emotional level. A loss of independence, general frustration and feelings of isolation were each mentioned a number of times at the workshops.

# **Emotions and personal challenges**

Loss of independence General frustration (e.g. ability to attend outings or appointments) Feeling of isolation Challenging behaviour Loss of attention/memory

# 4.3. Suggested changes

The final question asked at the community workshops was "If you could make changes in your community, what would a dementia friendly community look like or include?" Suggested changes were mostly in relation to changing attitudes and awareness around dementia including education and training, as well as creating dementia friendly services and facilities.

Five high-level categories have been used to group the responses; attitudes, awareness and education, dementia friendly services and facilities, medical and government services, carer support and social and community

All comments have been themed and organised under these five categories. Again, comments are ordered according to the prevalence during the community workshops.

# 4.3.1. Attitudes, awareness and education

Education and training about dementia targeted at young people was seen as a key change that could be made to promote dementia friendly communities. Education and awareness targeted at the general public was also frequently mentioned. Education and training was suggested for a broad range of professions that interact with people with dementia, particularly retail businesses, the service industry and health professionals.

Suggested approaches to an awareness campaign include using a high profile advocate and television advertising. Reducing and removing stigma should be considered a focus for such education and awareness initiatives.

# **Education and training**

For school students / children / youth / community service for young people For staff (e.g. general services industry, front line staff, tradespeople) Educate community members / general public For businesses / retail / shops For health professionals (e.g. doctors, nurses, dentists) For local government workers (e.g. library) For police For security By people with dementia In rural and outer suburbs

# Awareness / awareness campaigns

Increase general community awareness / understanding High profile people to advocate for dementia (e.g. Hazel Hawk, Ita Butrose, music and sports personalities) Television advertising on dementia Awareness campaign (e.g. to schools, service providers, media, dementia week) Dementia friendly accreditation / endorsement for businesses (e.g. Dome café)

Increase awareness about support services / help available

### Attitudes and acceptance

Reduce or remove stigma More acceptance (general / community) Compassion Having a sense of safety and security More patience and respect / listening To be treated like an individual

# 4.3.2. Dementia friendly services and facilities

Improving existing services and facilities or introducing new services or facilities was commonly mentioned as a possible change at the workshops. Particularly in relation to better transport (e.g. specific bus services) and improved walking surfaces, increased and improved signage and access to dementia friendly toilets.

Running respite facilities using a 'village' model was also suggested.

### Dementia friendly services

Better transport (e.g. bus service to appointments) Dementia specific information hub (e.g. online, accessed at care centre or key facilities, covering info for carers) Increase awareness of available dementia friendly services, and how to access In home care (e.g. like the village-style residential care facility ' Hogewey' in the Netherlands)

#### Dementia friendly facilities and signage

Wider / smoother footpaths / ramps
Increased access to dementia friendly toilets (e.g. toilet seats different colour to floor)
Better signage (e.g. bigger and with pictures / symbols as well as words)
More dementia specific facilities in the community
Community planning to include and improve dementia and disability enabling facilities
More seating available (e.g. at shopping centres)

#### **Respite facilities**

Village / cottage environment (e.g. run by doctor, for people living independently) Overnight respite Respite house / lodge

# 4.3.3. Medical, government and legal services

Commonly mentioned improvements to medical, government and legal services include education and training for General Practitioners and increased funding from government.

# Medical, government and legal services

Education and training for GPs and health professionals More funding for education and training More information distribution from GP's (e.g. regarding dementia support groups) Easier to manage changes to power of attorney

# 4.3.4. Specific approaches / treatments

A wide range of specific approaches to help make communities more dementia friendly were discussed without any single suggestion being particularly common. Interesting suggestions include use of identification bracelets, alarms and Global Positioning System devices, and increased use of colour, for instance, as part of table settings.

# Specific approaches or treatments

Identification bracelet / medical alarm / Global Positioning System Entertainment and activities (e.g. in residential respite centres) Increased use of bright colours (e.g. bright coloured table settings) secure important items to a lanyard / in a "man bag" Animals therapy Sharing activities with children

# 4.3.5. Carer support

Carers clearly need to be considered when focussing on making community's dementia friendly. Support groups were commented on as helpful for carers particularly in relation to managing their own mental and physical health.

# **Carer support**

Support groups for carers (e.g. workshops to help with their mental and physical health) Training for carers (e.g. learning about ways to encourage the person with dementia to maintain a level of independence, upskilling young carers)

# 4.3.6. Social & community

Increased access to social groups and activities for people with dementia and their carers was mentioned a number of times in the workshops.

# Social and community

Dementia friendly community activities / social groups (e.g. dementia focussed social groups, café catch ups)

Neighbour support / relationships.

# **5. DETAILED FINDINGS BY LOCATION**

I	
	FLOREAT

FLOREAT		
POSITIVES	FRUSTRATIONS / BARRIERS	
<ul> <li>Community/ Community Group</li> <li>Community Care and Support <ul> <li>Supportive neighbourhood/ community (2)</li> <li>Education and information</li> <li>Community engagement with Elizabeth</li> </ul> </li> <li>Community Groups <ul> <li>Volunteering inclusion (2)</li> <li>Walking Group</li> <li>Choir</li> </ul> </li> <li>Services <ul> <li>Services providing for the needs of people living with dementia</li> <li>Home care for pet needs</li> <li>Library providing resources</li> <li>Carer information sessions</li> <li>Technological support</li> </ul> </li> <li>Services providing support for people with dementia <ul> <li>Association providing golf companion</li> <li>Gym – support and rule changes (2)</li> </ul> </li> <li>Family Support</li> </ul>	<ul> <li><u>Doctors / Medical / Government systems</u></li> <li>Medical Service <ul> <li>Lack of understanding</li> </ul> </li> <li><u>Lack of understanding</u></li> <li><u>attitudes/awareness/education</u></li> <li>Negative attitudes by community (ignorance) (2)</li> <li>Lack of Awareness</li> <li>Lack of support for families</li> <li><u>Services / Facilities</u></li> <li>Amenities <ul> <li>Signage (toilets) (2)</li> </ul> </li> <li>Physical Environment <ul> <li>Mirrors (2)</li> <li>Steps / stairs (2)</li> <li>Flooring (patterned carpet, shiny flooring)</li> <li>(2)</li> <li>Windows / glass</li> <li>Loud Noises - Music / Announcements</li> <li>Latches</li> <li>Taps</li> </ul> </li> <li>Difficulty in accessing support for carers (2)</li> <li>Travel</li> <li>Difficulty of going on outings</li> </ul> <li>Emotions and personal challenges</li> <li>Feeling of isolation</li> <li>General frustration <ul> <li>Unable to play sport</li> </ul> </li>	
<ul> <li>CHANGES FOR A DEMENTIA-FRIENDLY COMMUNAL</li> <li>Attitudes / Awareness / Education</li> <li>Education and Training         <ul> <li>Training for staff (2)</li> <li>Education for more tolerance</li> <li>Education and Training for service industry</li> <li>Education and training for service industry</li> <li>Education and training for school students</li> <li>Have champions to promote and educate</li> </ul> </li> <li>Attitudes and Acceptance         <ul> <li>Feel welcomed in every shop and premises</li> <li>Community safety</li> </ul> </li> </ul>	NITY	

# FLOREAT

- Awareness
  - Inform neighbours and neighbourhood services (e.g. banks, dentists)
  - o Consider linking dementia issues with sport (like breast and prostate cancer campaigns)
  - o Linking dementia issues to music

# Facilities and services

- Signage
  - o Bigger signage
- Dementia friendly public facilities
  - More seating available
  - Simplify basic facilities
    - Better access to toilets
    - Toilet seats different colour to floor
    - Notify local council about park toilets to be dementia-friendly
- Services
  - $\circ~$  Out of hours services (i.e. Neighbourhood Watch equivalent for crisis moments)

WANNEROO		
POSITIVES	FRUSTRATIONS / BARRIERS	
Business         OBUSINESS awareness         Community/ Community Group         Community attitude / approach (3)         Youth approach (2)         Community Groups         Men's Shed         Choir         Volunteering         Bowling club         Walking group         Services         Service         Uibrary Staff         Local Gym         Hostess on plane         Taxi Service (UK)         Family and social         Friends         Meeting new people when walking dog         Friends who take time to understand	<ul> <li><u>Doctors / Medical / Government systems</u></li> <li>Appointments <ul> <li>Lack of flexibility</li> </ul> </li> <li>Medical Service <ul> <li>Reluctant GP</li> <li>Lack of education for families and carers</li> </ul> </li> <li>Government <ul> <li>Lack of information regarding legislation changes</li> <li>Lack of clarity about driving and when one needs to be tested in order to keep their license</li> </ul> </li> <li>Lack of understanding <ul> <li>attitudes/awareness/education</li> </ul> </li> <li>Lack of understating (2)</li> <li>Social Isolation</li> <li>Services / Facilities</li> <li>Amenities <ul> <li>Signage for toilets (3)</li> <li>Signage for Public Transport</li> </ul> </li> <li>Services <ul> <li>Door to door sales/ scams</li> </ul> </li> <li>Physical Environment <ul> <li>Lack of seating</li> <li>Steps and stairs</li> </ul> </li> </ul>	

# WANNEROO

# **CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY**

# Attitudes / Awareness / Education

### • Education and Training

- Educating general public (2)
- Education and training at banks
- Education and training for transport workers
- Education for staff
- News, Media and Advertising
  - Advertising campaigns
  - TV advertising
  - Radio advertising
- Awareness
  - o High profile people to advocate for dementia
  - People who listen and care
  - Endorsed business such as Dome Café who support people with Dementia

# Facilities and services

- Signage
  - o Better signage
- DFC Facilities
  - Better infrastructure (i.e. footpaths)
- Services
  - Tighter regulations regarding sales (e.g. people in shopping centres that talk the person with dementia in to setting up a direct debit payment for a product or service)

# Carer support

- Carer Support
  - Greater support for carers
  - o Flexible respite
  - o Conversion of sick leave to carers leave for parents

# Social /Community

- Social Groups
  - Keep in contact with others in the area
  - Regular café catch-ups

#### Medical / Government / Legal Services

- Improved / increased medical services
  - Support for men living with dementia
- Government
  - Better planning and regulation for Dementia Friendly areas and house

#### ROCKINGHAM POSITIVES **FRUSTRATIONS / BARRIERS** Doctors / Medical / Government systems Business • Business awareness Medical Service Community/ Community Group Hospital • Community Care and Support - Feeling like of prisoner - Lack of wheelchair availability Community is helpful / caring (5) Community knowledgeable • Lack of information from GP (3) Government Community Groups • Lack of care Sporting clubs (2) Lack of funding Services Services providing for the needs of people living Lack of understanding with dementia attitudes/awareness/education • Parkinson's Support (2) • Lack of family / friend support (2) Specialist Support • Social Isolation (2) • Services providing support for people living with Services / Facilities dementia Amenities • People who care Supermarket layout Prime mover organisers Limited facilities Local Library Services Family and social • Public Transport / unable to drive (4) - Local Government has a bus but carer • Family Support (3) • Friends (7) not allowed to come • Lack of respite / community care (2) • Have a laugh with friends (2) • Support from community group friends • Day facility provides lack of stimulation (golf club) o Autumn centre Lack of help at service station Facilities Recreational facilities (i.e. pool) Physical Access Issues Accessible to small gopher Lack of walker/wheelchair access Public transport Public toilets Individual Care • Enjoyable Activities (i.e. games, cards, quiz) **CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY** Attitudes / Awareness / Education • Education and Training • Education and training for council workers

- Education and training for community/public
- Education and training in schools
- Education on first signs of dementia
- Awareness
  - More community awareness (2)
  - Awareness of help available
- Stigma
  - Strategies to reduce stigma <u>Facilities and services</u>

# ROCKINGHAM

- Respite Facility
  - Village similar to a set up in Holland, run by a doctor
- DFC Facilities
  - Better transport facilities (e.g. weekend service) (3)
  - Stimulation more facilities
  - Better infrastructure (i.e. footpaths)
  - More available meeting areas
- Services
  - Awareness of services available
  - o Community organisation to have a dementia representation
  - $\circ$   $\,$  Information on how to access a service
- Carer support
- Carer Support
  - $\circ \ \ \text{More training}$

Medical / Government / Legal Services

- Improved / increased medical services
  - More information around support from GPs

Specific approaches or treatments

- Preventative measures
  - More nutritional measures

# MANDURAH

	1
POSITIVES	FRUSTRATIONS / BARRIERS
<ul> <li><u>Business</u></li> <li>Business awareness (2)</li> <li><u>Community/Community Group</u></li> <li>Community Care and Support <ul> <li>Community awareness (3)</li> <li>Community willing to learn more</li> </ul> </li> <li>Community Groups <ul> <li>Explorer club (2)</li> <li>Men's Shed (2)</li> <li>Bike club</li> <li>Church groups</li> <li>Gardening Club</li> <li>Scrabble program</li> <li>Village vegie patch</li> </ul> </li> </ul>	<ul> <li><u>Doctors / Medical / Government systems</u></li> <li>Communication         <ul> <li>Lack of relationship building</li> </ul> </li> <li>Lack of education about high care facilities(2)     </li> <li><u>Lack of understanding</u> <ul> <li>attitudes/awareness/education</li> <li>Lack of communication</li> <li>Lack of understanding / patience (6)</li> <li>Lack of knowledge / education</li> </ul> </li> <li>Services / Facilities         <ul> <li>Lack of signage</li> <li>Lack of parking</li> </ul> </li> </ul>
<ul> <li>Boat trip to Bunbury</li> <li>Services</li> <li>Services Catering for PWD needs <ul> <li>Hospital staff (2)</li> <li>Carers</li> <li>Dawn</li> <li>Alzheimer's Australia WA –Mandurah office</li> </ul> </li> <li>Services Caring/looking out for PWD <ul> <li>Silver Chain (2)</li> <li>Meals on Wheels</li> <li>House cleaners</li> <li>Accommodation</li> </ul> </li> <li>Family and social <ul> <li>Family Support (2)</li> <li>Friendship groups (7)</li> <li>Social groups (2)</li> <li>Sharing Experience / knowledge (5)</li> <li>Facilities</li> <li>Public Transport</li> </ul> </li> </ul>	<ul> <li>Difficulty in accessing support for carers (2)         <ul> <li>Travel</li> <li>Difficulty of going on outings</li> </ul> </li> <li>Services         <ul> <li>Lack of respite care (2)</li> <li>No one stop shop to find information (2)</li> <li>Lack of advertising of services</li> </ul> </li> <li>Physical Environment         <ul> <li>Floor (4)</li> <li>Noises (2)</li> <li>Chairs</li> </ul> </li> <li>Emotions and personal challenges</li> <li>Loss of independence (3)</li> <li>Loss of attention/memory (2)</li> <li>Other:             <ul> <li>Feeling frightened</li> <li>Not ready to be put in respite</li> <li>Lack of stimulation</li> </ul> </li> <li>General frustration         <ul> <li>Ability to attend outings or appointments (2)</li> </ul> </li> <li>Physical Access Issues</li> <li>Lack of walker/wheelchair access (2)</li> </ul>

# MANDURAH

# **CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY**

### Attitudes / Awareness / Education

- Education and Training
  - o Educational information for Boards

### Facilities and services

- Services
  - o Quicker support
  - Domestic help rules simplified (i.e. insurance liability limits the help)
- Transport
  - o Better transport
- DFC Facilities
  - o Better seating at shopping centre
  - Numbers on individual car parks
- Respite Facility
  - For people living on their own in retirement village
- Carer support
- Respite Care
  - $\circ$  Improvement of respite care
- Carer Support
  - Attend meetings after partner is in other care

### Social /Community

- Social Groups/Activities
  - o Increase in activities in local centres
  - More outings
- Buddy System
- Specific approaches or treatments
- Learning / Re-education
  - How to tell the time
- Sharing activities with children
- Preventative measures
  - $\circ$   $\,$  Work for the dole

MIDLAND	
POSITIVES	FRUSTRATIONS / BARRIERS
<ul> <li><u>Business</u></li> <li>Business awareness (4)</li> <li><u>Community/Community Group</u></li> <li>Community Care and Support <ul> <li>Person with dementia living in the community</li> </ul> </li> <li>Community Groups <ul> <li>Men's Shed (3)</li> <li>Tattoo Group</li> <li>Church</li> </ul> </li> <li>Volunteering <ul> <li>Services</li> </ul> </li> <li>Services Catering for PWD needs <ul> <li>Swan community Care (2)</li> </ul> </li> </ul>	<ul> <li><u>Doctors / Medical / Government systems</u></li> <li>Staff have lack of awareness</li> <li><u>Services / Facilities</u></li> <li>Amenities         <ul> <li>Lack of lighting</li> <li>Lack of colours</li> <li>Lack of parking</li> </ul> </li> <li>Difficulty in accessing support for carers (2)         <ul> <li>Travel</li> <li>Difficulty of going on outings</li> </ul> </li> <li>Services         <ul> <li>Lack of residential respite</li> <li>Lack of interaction in village</li> </ul> </li> </ul>
<ul> <li>HACC Day Centre (2)</li> <li>Family and social</li> <li>Family Support (2)</li> <li>Friendships (3)</li> </ul>	<ul> <li>Steps / curbing</li> <li>Windows</li> <li>Emotions and personal challenges</li> <li>Fear from community</li> </ul>
	<ul> <li>Lack of family / friend support</li> <li>Feeling of isolation / loss of independence (4)</li> </ul>
<ul> <li>CHANGES FOR A DEMENTIA-FRIENDLY COMM</li> <li>Attitudes / Awareness / Education</li> <li>Education and Training <ul> <li>Education and training for children and year</li> </ul> </li> </ul>	
<ul> <li>Education and training for retail/shops</li> <li>Education for community</li> <li>Education for Police</li> <li>Education for Security</li> <li>Education and training for staff</li> </ul>	

- Education and training by people with Dementia
- In Rural and outer suburbs
- Awareness
  - o Families to have more understanding
  - Community to have more understanding (3)
  - High profile people to advocate for dementia (e.g. Hazel Hawke, Ita Buttrose) (2)
- News, Media and Advertising
  - Print media (brochure, stickers)
  - Recognisable logo
- Stigma
  - Increase community compassion (2)
  - o Remove Stigma

# MIDLAND

# Facilities and services

- Respite Facility
  - Residential Respite including entertainment
- DFC Facilities
  - Community planning to include and improve dementia and disability enabling facilities (2)

Carer support

- Carer Support
  - More compassion for carers
  - $\circ$  Support groups for carers

# Medical / Government / Legal Services

- Awareness
  - $\circ$  Distribution of information about support groups and education by Doctors and GPs

# Social /Community

- Community Support
  - Community leaders to bring people with dementia together (2)
  - Catering to disadvantage groups (i.e. Languages other than English)
  - $\circ$  More welcoming community groups

# Specific approaches or treatments

- Preventative measures
  - o Entertainment in residential respite centres

# ARMADALE

<u>Business</u>

•	Business Caring/looking out for person with
	dementia (3)

Community/ Community Group

- Community Care and Support
  - Community support & awareness (2)
  - Volunteers Day
- <u>Services</u>
- Services Catering for Person living with dementia's needs
  - Services focused on inclusion (3)
  - GP/ Doctor (2)
  - o Addie Mills Centre
  - Mental Health Team at Armadale Hospital
  - Library providing resources and information (2)
- Services Caring/looking out for PWD
  - Centrelink assistance
- Family and social
- Family Support (2)
- Friendships
  - Listening
  - $\circ$   $\,$  Feel appreciated in club  $\,$

# **FRUSTRATIONS / BARRIERS**

#### Doctors / Medical / Government systems

- Communication
  - Lack/no communication between GP and carer
  - Overall lack of communication from medical providers
- Safety
  - Placement of patient in hospital to feel safe and communicate with others
- Medical Service
  - Lack of awareness and understanding of patient limitations (3)
  - No home visits
  - Doctor not recognising problem
  - Lack of interested in mental condition
- Appointments
  - Unable to remember appointments
- Government
  - Lack of care and understanding from Centrelink (3)

# Lack of understanding

# attitudes/awareness/education

- Negative Attitude
  - Disrespectful (i.e. communication) (3)
  - Judgemental
- Lack of understanding by general public (2)
- Lack of family support and understanding (i.e. family in denial) (3)

#### Services / Facilities

- Amenities

   Lack of signage / Navigation tools (3)

   Physical Environment
  - Street signs (2)
- Services
  - Poor interaction with services (i.e. Silver Chain)
- Other:
  - Not phone friendly
  - Difficulty of going on outings

# ARMADALE

# CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY

# Attitudes / Awareness / Education

- Education and Training
  - More Education and Training
  - Trained Staff in hospitals and homes
  - o School / student community service
- Attitudes and Acceptance
  - To be treated like an individual (2)
  - People's attitude
  - o Acceptance
  - More patience and respect
  - People to stop and listen to us
- News, Media and Advertising
  - o Television Advertising on Dementia
- Awareness
  - o More public awareness and understanding of what Dementia is

# Facilities and services

- DFC specific services
  - In-Home care, (like the village-style residential care facility 'Hogewey' in the Netherlands)
- Signage specific to people with Dementia (2)
- Dementia friendly public facilities
  - o Dementia accessible
  - Disabled toilets

# Carer support

- Respite Centres
  - $\circ$  More respite, day centres and hospitals for people with dementia and their carers
- Family Support
  - Family group space / place to speak to medical professionals

# Medical / Government / Legal Services

- Education and Training
  - Educate Health Professionals
- Improved / increased medical services
  - More Occupational Therapists on weekends
- Government Funding
  - More Government Funding (2)
  - o Funding for residential care staff
- Government Support
  - $\circ~$  Greater assistance from Centrelink

# Social /Community

- Community Awareness
  - o Talking to people in your neighbourhood

# Specific approaches or treatments

- Preventative measures
  - Massage to help with relaxation

# ARMADALE

- Spatial / Visual approach
  - Use of bright colours
    - Bright coloured table settings (e.g. China)
    - Coloured paper for readability
    - $\circ\,$  Visual Calendars
    - Pictures on menus
- Ideas to assist with independence
  - o Attach important items to a lanyard
  - Place essential items in a 'man bag'
  - $\circ~$  Tie ribbon to door in a hotel
  - Keep writing materials on hand

<u>Costs</u>

# • Cheaper dementia-friendly equipment (e.g. large-face clocks)

### MELVILLE

### CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY

### Attitudes / Awareness / Education

- Education and Training
  - o Education and training for retail/shops
  - Education for community
  - Education for Police
  - Education for Security
  - $\circ \quad \text{Education and training for staff}$
- Awareness
  - o General Awareness
  - o Awareness of Alzheimer's profile to medical professionals and community
  - o Awareness Campaign
    - Hold a 'Dementia Week'

### MELVILLE

- Campaign to schools, service providers, media

### Facilities and services

- Services
  - o Excellent communication between agencies to share information
  - $\circ$   $\;$  Introduce a 'system' that checks on wellbeing on client
  - Gender carer matching i.e. male company for male person with Dementia
  - o Employee to be delegated to offer more assistance to those with dementia
- In-Home Care
  - More practical home assistance

### Carer support

• More Carer support with household chores (e.g. gardening)

### Medical / Government / Legal Services

- Improved / increased medical services
  - More Dementia-friendly GPs (3)
  - More support from GPs (2)
  - More resources
- Government Support
  - LGA to have a one stop shop of information
  - More government leaderships and 'Buy in'
- Funding
  - o Increase in funding

### Social /Community

- Neighbourhood
  - o Support
  - $\circ$  Education
  - o Awareness
  - Better relationships with neighbours
- Community Spirit

### Specific approaches or treatments

- Preventative measures
  - More opportunities to exercise

### <u>Costs</u>

• Reasonable cost for practical home assistance

### BUNBURY

<u>Business</u>

- Business Caring/looking out for PWD (2)
   <u>Community/Community Group</u>
- Community Care and Support
  - $\circ$  Dementia Friendly community
  - Neighbourhood support
- Community Groups
  - Men's Shed
  - Dalyellup Community Centre

<u>Services</u>

- Services providing for the needs of people living with dementia
  - Respite / care centre (4) (Highcare, Morrisey, Bethanie)
  - NCWA linking with support services
- Services providing support for people living with dementia
  - Services sending text messages about appointment reminders

Family and social

- Family Support (3) Facilities
- Outdoor Facilities
  - Gardens
  - Public Parks

Individual Care

- Individual Care Independence/Care
  - Pictures and Photos
- Challenging behavioural experiences

   Unplanned activities

• Family stresses

**FRUSTRATIONS / BARRIERS** 

Communication

Medical Service

Lack of understanding

family in denial)

Physical Environment

Lack of lighting

support) (2)

• Lack of local services

• Not phone friendly

Emotions and personal challenges

Services / Facilities

Amenities

Services

• Other:

Government

Doctors / Medical / Government systems

medical providers

Lack of collaboration

Centrelink (3)

attitudes/awareness/education

General Amenities

• Access in shopping centres

• Loud music / Announcements

• Difficulty of going on outings

• Overall lack of communication from

• Lack of care and understanding from

Lack of family support and understanding (i.e.

• Accessible floor surfaces (pavement)

Lack of services for carers (training and

### CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY

### Attitudes / Awareness / Education

- Education and Training
  - $\circ$  More community education
- Awareness
  - o Increase awareness about support services

### Facilities and services

- Respite facilities
  - o Village environment
  - $\circ \quad \text{Closer to home} \\$

### BUNBURY

- DFC specific services
  - $\circ$   $\,$  Care centre to take time out and gather information
  - Support groups
  - Delivery services to home (e.g. postage, shopping, meals)
- Signage
  - Specific to people with Dementia (e.g. include pictures, symbols)
  - Toilets to change signage to show Disability / Carers Toilets
- DFC public facilities
  - o Wider footpaths
  - Wider ramps

### Carer support

- Carer Support
  - Support groups for Carers
  - Workshops for Carers (e.g. to help with their mental and physical health)

Medical / Government / Legal Services

- Improved / increased medical services
  - $\circ$   $\,$  Access to Doctors when required

### ALBANY

### <u>Business</u>

- o Business awareness
- Café Emu Point aware of people with memory loss

### Community/ Community Group

- Community Care and Support
  - Community support & patience
     (4)
    - Emotion support
    - Guidance
    - Education
    - Supportive friendships
    - Humour

### <u>Services</u>

- Services providing for the needs of people living with dementia
- Hawthorn House (3)
- Fulltime nursing care
- o GP
- o Carer able to rest
- Red Cross / Mt Barker Group
- Services Caring/looking out for PWD
- Police happy to provide assistance

### Family and social

Family Support

### **Facilities**

- Facilities Provision for people living with dementia
- Training for staff
  - OH&S training to include introduction to Dementia
- Short break accommodation and visits Hawthorne House (2)

### **FRUSTRATIONS / BARRIERS**

### Doctors / Medical / Government systems

- Communication
  - Unable to understand questions (2)
  - Lack of education on how to communicate with people living with dementia
  - Lack of communication between service providers

### • Safety

- Lack of awareness
- Medical Service
  - Reluctant GP
- Appointments
  - Waiting times

### Lack of understanding

attitudes/awareness/education

- Negative Attitude and consideration (2)
- Lack of understanding (e.g. in acute settings) (2)
- Lack of family support (2)

### Services / Facilities

- Amenities (i.e. airports, library's, shopping centres)
  - Lack of signage / Navigation tools (3)
  - Shopping Centre checkouts (2)
- Physical Environment
  - Loud music / Announcements (2)
  - Design not for access (i.e. loose
  - mats/floors/surface, toilet entry) (2)
- Lack of specific services
- Transport Issues
  - $\circ$   $\,$  Lack of parking close to amenities
  - Waiting time for wheelchair taxi

• Other:

- Lack of training
- Refused Travel Insurance
- Emotions and personal challenges

### • Challenging behavioural experiences

- Physical Access Issues
- Lack of walker/wheelchair access (2)

### CHANGES FOR A DEMENTIA FRIENDLY COMMUNITY

Attitudes / Awareness / Education

- Education and Training
  - Education and Training for school students (4)
    - School Community Service

### ALBANY

- Education and Training for Retail / Shops (Coles) (2)
- Education and Training for Health Service providers (Nurses, Dentists) (2)
- Education and Training for Local Government Centres (Library)
- $\circ$   $\;$  Obtain a First Aid Certificate when applying for Drivers Licence
- News, Media and Advertising
  - o Television Advertising on Dementia (2)
  - Regular slots in newspapers or magazines
- Stigma
  - Reduce Stigma
  - Remove Stigma
- Greater awareness of needs of people with Dementia and their carers

### Facilities and services

- Respite facilities
  - Overnight respite (2)
  - Small cottage like living centres
  - Specific day or time set aside for quiet time
  - Dementia friendly specific services
    - o In-home care
    - $\circ$   $\;$  Support structure to assist families and work through issues
- Dementia friendly specific facilities
  - o More dementia-specific facilities in the community
- Dementia friendly public facilities
  - o Sufficient disability access (e.g. car parking and toilets)

### Carer support

- Training for Carers
  - o Learn the process to allow the person with dementia to have a level of independence
- Carer Support
  - Volunteers to provide support through visiting those who live alone

### Medical / Government / Legal Services

- Education and Training
  - o Educate GPs and Allied Health Professionals
  - $\circ$   $\;$  Training for Hospital and Government Department staff and professionals
- Improved / increased medical services
  - Symptom focused services
- Legal Representation
  - Family member to have power of Attorney

### Social /Community

• Dementia-friendly community activities

### Specific approaches or treatments

- Medical Identifier
  - $\circ$  Logo that shows person has an impaired ability to communicate or understand
  - Medical Alarm / GPS System
  - $\circ \quad \text{Identification bracelet} \\$

### NORTHAM

### NORTHAM

### CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY

### Attitudes / Awareness / Education

### • Education and Training

- Education and training for businesses (2)
- Education for community
- Education for Police
- Education for Security
- Education and training for staff
- Education and training by people with Dementia
- o In Rural and outer suburbs
- Awareness
  - o Dementia friendly accreditation for businesses
- Stigma
  - o Increase community compassion

### Facilities and services

- Respite Facility
  - Respite house / lodge (2)
  - o Residential care facilities to be more dementia friendly
  - o Drop in centre for people living independently
- DFC Facilities
  - More facilities
  - Smoother footpaths
- Services
  - o Bus service to take people to appointments and services
  - More people to work in the industry
  - More regular access to local specialist

### Medical / Government / Legal Services

- Improved / increased medical services
  - o Doctors to not prescribe drugs for an easy fix
  - Mobile medical centre
- Government
  - o Government to intervene in rules and regulations in residential care facilities
- More Funding

### Social /Community

- Social Groups
  - o More social opportunities
- Community Attractions
  - $\circ$   $\,$  No community attractions to attend with people living with dementia
- Specific approaches or treatments
- Medical Identifier
  - Alert / Identification bracelet or necklace

## KALGOORLIE

KALGOORLIE		
POSITIVES	FRUSTRATIONS / BARRIERS	
<ul> <li><u>Community/Community Group</u></li> <li>Community Care and Support         <ul> <li>School Visits</li> </ul> </li> <li>Services</li> <li>Services providing for the needs of people living with dementia         <ul> <li>Communication</li> </ul> </li> <li>Services providing support for people with dementia         <ul> <li>Communication</li> </ul> </li> <li>Services providing support for people with dementia         <ul> <li>Men's Shed (2)</li> <li>Bingo</li> <li>Orana Cinemas</li> <li>Shopping centre</li> </ul> </li> <li>Family and social</li> <li>Family Support</li> <li>Facilities</li> <li>Outdoor Facilities         <ul> <li>Public parks (2)</li> <li>Sport / Recreation             <ul> <li>Swimming / water therapy (2)</li> <li>Gym</li> </ul> </li> <li>Individual Care         <ul> <li>Enjoyable Activities - i.e. listening to music, walks</li> </ul> </li> </ul></li></ul>	<ul> <li><u>Doctors / Medical / Government systems</u></li> <li>Appointments <ul> <li>Waiting times</li> </ul> </li> <li>Medical Service <ul> <li>Lack of dementia friendly services</li> </ul> </li> <li><u>Lack of understanding</u> <ul> <li>attitudes/awareness/education</li> </ul> </li> <li>Lack of communication</li> <li>Lack of understanding (2)</li> </ul> <li><u>Services / Facilities</u> <ul> <li>Amenities</li> <li>Lack of access and of utilities</li> </ul> </li> <li>Difficulty in accessing support for carers (2) <ul> <li>Travel</li> <li>Difficulty of going on outings</li> </ul> </li> <li>Services <ul> <li>Lack of services</li> <li>Lack of help for respite</li> </ul> </li> <li>Physical Access Issues</li> <li>Lack of walker/wheelchair access (2)</li>	
<ul> <li>and interaction with animals- (2)</li> <li>CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY</li> <li>Facilities and services</li> <li>Services</li> <li>Services to be accessible</li> <li>Day Care / Respite for advanced stages of de</li> <li>Dementia-specific information hub to advise</li> <li>Transport</li> <li>Transport to be accessible</li> <li>Dementia- friendly Facilities</li> <li>Art Centre</li> <li>Telephones to use in facilities</li> <li>Development of an activity / socialising cent</li> <li>Social /Community</li> <li>Social Groups</li> <li>Increase in specific social groups</li> <li>Independence</li> <li>More opportunities to go outside and visit p</li> </ul>	ementia e and help carers tre	

### KALGOORLIE

### Specific approaches or treatments

- Animals therapy (2)
- Outdoor activities
- Visits with Children
- Music / Singing therapy
- Improvement of memory
  - Teaching people individual skills

#### GERALDTON POSITIVES **FRUSTRATIONS / BARRIERS** Community/ Community Group Doctors / Medical / Government systems Community Care and Support Medical Service • Supportive neighbourhood/community (2) Medications • Lack of coordination • Community Groups • Explorer club (2) Government • Men's Shed (2) Financial Support Bike club • Centrelink • Church groups Lack of understanding • Gardening Club attitudes/awareness/education • Scrabble program Lack of knowledge / education (3) • Village vegie patch • Lack of family support (denial) (5) • Boat trip to Bunbury Services / Facilities <u>Services</u> Amenities Services providing for the needs of people living Signage with dementia Physical Environment • Respite / Day Centres (2) o General Physical Environment not fit for Centrelink those with a disability (3) • Services providing support for people living with • Difficulty in accessing support for carers (2) dementia o Travel • Carers (2) • Difficulty of going on outings • Silver Chain (2) Services o RSL • Lack of services (or knowledge of) (4) • Bethanie • Lack of activities and support groups (2) Family and social • Being invoiced for meals and transport for Friendships (3) day centre Individual Care • Training for careers Enjoyable Activities (i.e. art projects) • Lack of trust in support service workers • Business not letting family / carer talk on behalf of person with a diagnosis of dementia Emotions and personal challenges • Feeling of isolation (3) • General frustration • Ability to go on outings or attend appointments (2)

### GERALDTON

### CHANGES FOR A DEMENTIA-FRIENDLY COMMUNITY

### Attitudes / Awareness / Education

- Education and Training
  - Education and training for shop / retail / Government (Centrelink) bank staff (3)
  - Education and training for health professionals
  - Education and training for school students
  - Educate community members
- Attitudes and Acceptance
  - More advocacy for people living with dementia
  - Having a sense of safety and security

### Facilities and services

- Signage
  - Better signage (i.e. for roads, symbols as well as words)
- Dementia Friendly public facilities
  - Supermarkets to have wider aisles for better access
  - Parks to be more accessible
  - o More dementia-specific care facilities (i.e. respite, residential care facility)
    - Need more staff
  - o Requirements/regulations for buildings to be Dementia friendly
- Services
  - o Development of an Information Hub Online
    - Interactive section on WA Dementia website (forum) / Info (network) about workshops
  - Central place for information for carers (i.e. Hospital, Library, Local Government, Community Resource Centre, Web, Silver Chain or Home And Community Care)

### Carer support

- Carer Support
  - Support groups for Carers
- Family Carer Support
  - More support
  - Young family carer's upskilling assistance

### Medical / Government / Legal Services

- Improved / increased medical services
  - o Central medical records
- Legal Representation
  - Make it easier to obtain power of Attorney earlier
- Government Support
  - $\circ$   $\;$  Centrelink to be a lot more understanding
- Funding
  - Funding for art activities
  - Funding for respite services
  - Funding for more staff

### Specific approaches or treatments

- Preventative measures
  - Entertainment and activities
  - Exercise classes to establish a routine and social connection

ESPERANCE		
POSITIVES	FRUSTRATIONS / BARRIERS	
<ul> <li><u>Business</u></li> <li>Business providing support for people living with dementia (2)</li> <li><u>Community/Community Group</u></li> <li>Community Care and Support</li> <li>Community Groups <ul> <li>Senior Citizens</li> <li>Walking Group</li> <li>Choir</li> <li>Alzheimer's Association Talks</li> </ul> </li> <li>Services <ul> <li>Services providing for the needs of people living with dementia</li> <li>Home / Day Care (5)</li> <li>Reflexology appointments</li> </ul> </li> <li>Family and social</li> <li>Friendships (2)</li> </ul>	<ul> <li><u>Doctors / Medical / Government systems</u></li> <li>Lack of education and training (2)</li> <li>Negative attitudes</li> <li><u>Services / Facilities</u></li> <li>Amenities <ul> <li>Signage (toilets)</li> </ul> </li> <li>Physical Environment <ul> <li>Windows / glass panels (2)</li> <li>Steps / stairs (2)</li> <li>Flooring</li> <li>Loud music / Announcements</li> </ul> </li> <li>Other: <ul> <li>Travel</li> <li>Difficulty of going on outings</li> </ul> </li> </ul>	
<ul> <li>CHANGES FOR A DEMENTIA FRIENDLY COMMUNAL</li> <li>Attitudes / Awareness / Education</li> <li>Education and Training <ul> <li>Educate health professionals</li> <li>Educate staff</li> <li>School based program</li> <li>Family conferences</li> </ul> </li> <li>Attitudes and Acceptance <ul> <li>More acceptance</li> </ul> </li> <li>Facilities and services</li> <li>Signage <ul> <li>Standardised signage</li> </ul> </li> <li>DFC public facilities <ul> <li>To have less glass</li> <li>To have softer lighting</li> <li>Dementia-friendly buildings</li> <li>Quiet rooms to be respectful of people with</li> </ul> </li> </ul>		

### 6. APPENDICES

### 6.1. DEMENTIA FRIENDLY COMMUNITIES (DFC) -CONSULTATION FORMAT

#### 10:00 WELCOME

(10 min) Tea/ coffee served

Guests seated, introductions and connections made by Althea/ Liz on arrival

#### 10:15 Icebreaker

(15 min) Individual tables;

"Why you are here today" and "What are you hoping to get out of today" Group discussion, tables share their main points

10:30 INTRO - DFC

#### (15min) DFC Project Intro

Purpose of consultation/ our expectations/ reasoning \*Simple slides to accompany intro for visual support in the 3 areas\*

#### 10:45 CONTENT

(10 min) Chosen three questions (DFC so broad)

Process - how delivered (one question asked then discussed, examples will be given for clarification and guidance etc.)

Q1 - In regards to living with dementia in your community, what has been a **positive experience** for you and your family? (10 min)

Q2 - In regards to living with dementia in your community, what has been a **frustration or barrier** for you and your family? (10 min)

Q3 - If you could make **changes in your community**, what would a dementia-friendly community look like or include? (20 min)

11:25 WRAP UP

(5-10min)Thank you

Where to from here?

Liz- Dementia Advocacy Program plug (one slide)

11:30 FINISH

### **Question Delivery Layout**

#### Format

Ask the Question Spiel to put question into community context Examples of areas of discussion relating to the question Allow discussion

### 6.2. Detail on the Workshops

Below are the details of the thirteen workshops:

- Floreat Town of Cambridge
   Date: 10 December 2014
   Venue: Floreat Boulevard Centre, Shop 94,
   Floreat Forum, The Boulevard
   Attendees: 19
   Groups/tables: 4
- Wanneroo City of Wanneroo Date: 2 February 2015 Venue: Butler Community Centre, 55 Kingsbridge Boulevard Attendees: 19 Groups/tables: 4

### 3. Rockingham – City of Rockingham

Date: 6 February 2015 Venue: Gary Holland Community Centre, 19 Kent Street Attendees: 42 Groups/tables: 8

#### 4. Mandurah – City of Mandurah Date: 6 February 2015

Venue: Ac-cent Seniors Centre Mandurah, 41 Ormsby Terrace Attendees: 51 Groups/tables: 10

#### Midland – City of Swan Date: 10 February 2015 Venue: Old Midland Courthouse, 24 Spring Park Road Attendees: 20 Groups/tables: 4

### 6. Armadale – City of Armadale

Date: 13 February 2015 Venue: Piara Waters Pavilion, Wright Road (off Nicholson Road) Attendees: 35 Groups/tables: 6

### 7. Melville – City of Melville

Date: 18 February 2015 Venue: Melville Bowling Club, Canning Hwy Attendees: 29 Groups/tables: 6

#### 8. Bunbury – City of Bunbury

Date: 19 February 2015 Venue: SJOG Conference Rooms Bunbury, Cr Robertson Drive and Bussell Highway Attendees: 23 Groups/tables: 6

#### 9. Albany – City of Albany

Date: 25 February 2015 Venue: Hawthorne House, Henry Road Attendees: 26 Groups/tables: 5

#### 10. Northam – Shire of Northam

Date: 4 March 2015 Venue: Northam Recreation Centre, Peel Terrace Attendees: 25 Groups/tables: 5

#### 11. Kalgoorlie – City of Kalgoorlie-Boulder

Date: 12 March 2015 Venue: Eastern Goldfields Community Centre, Roberts Road Attendees: 17 Groups/tables: 3

#### 12. Geraldton – City of Greater Geraldton

Date: 18 March 2015 Venue: Bert Pepperell Training Centre Geraldton, 4 Walton Close Attendees: 17 Groups/tables: 3

#### 13. Esperance – Shire of Esperance

Date: 25 March 2015 Venue: Esperance Lotteries House, Forrest Road Attendees: 10 Groups/tables: 3

### 6.3. Marketing and Communications Plan

# Alzheimer's Australia WA Living with Dementia Workshops Marketing and Communication Plan

### Prepared by Creating Communities Australia

#### Event Details:

Location	Date	Workshop Venue	Time
Floreat	10 December 2014	Boulevard Centre, 99 The Boulevard	10am
Wanneroo	2 February 2015	Butler Community Centre, 55 Kingsbridge Boulevard	10am
Rockingham	6 February 2015	Gary Holland Community Centre, 19 Kent Street	10am
Mandurah	6 February 2015	AC-Cent Mandurah - 41 Ormsby Terrace	2pm
Midland	10 February 2015	Old Midland Courthouse, Helena Street	10am
Armadale	13 February 2015	Piara Waters Pavilion, Corner Wright Road and Nicholson Road	10am
Melville	18 February 2015	Melville Bowling and Recreation Centre, 592 Canning Highway	10am
Bunbury	19 February 2015	St John of God Conference Centre, Subiaco Clinic,CornerRobertson Drive & Bussell Highway	10am
Albany	25 February 2015	Hawthorn House, 40 Henry Street	10am
Northam	4 March 2015	Northam Recreation Centre, Henry Street Oval	10am
Kalgoorlie	12 March 2015	Eastern Goldfields Community Centre, 13 Roberts Street	10am
Geraldton	18 March 2015	Bert Pepperell Training, 4 Walton Close	10am
Esperance	25 March 2015	Esperance Lotteries House, 3 Forrest Street	10am

### Strategy

The Living with Dementia Workshop will be promoted to the local and broader community and stakeholders, using a mix of traditional PR activities, communication materials and direct promotion, and also tapping into established local networks.

A key strategic focus is to cultivate an awareness of the work of Alzheimer's Australia WA toward exploring the opportunities for establishing dementia friendly communities within the state, and to be used in the community as an informative qualitative study to get the issues out there.

### 6.4. Promotional Flyer and Posters

Example: Albany (Note: location and date updated for each workshop)



# Living with Dementia

Join us at your local community cafe to become a powerful voice making a difference for those living with dementia in WA

People living with dementia offer a unique perspective on their journey and experiences. We want to learn from your experience in order to understand what it's like to live with dementia in your community.

The high tea will commence at 10am, except Mandurah which will commence at 2pm.

13<sup>TH</sup> February 2015 PIARA WATERS PAVILION Wright Road (off Nicholson Road) Piara Waters, WA

RSVP is essential. To RSVP, please contact Veronica Keltie on 9388 2800 or register online at: <u>https://wa.fightdementia.org.au/community-cafe</u>

Sponsored by the Social Innovation Grants Program

Brought to you by:







### **Promotional Poster**



# Living with Dementia

# Join us at your local community cafe to become a powerful voice making a difference for those living with dementia in WA

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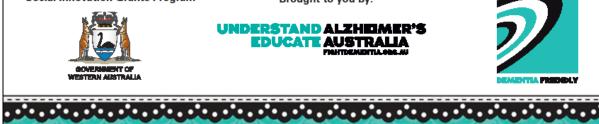
Bunbury	19 F
Albany	25 I
Northam	4
Kalgoorlie	12
Geraldton	18 I
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Sponsored by the Social Innovation Grants Program

Brought to you by:



### 6.5. Media Releases

### Mandurah Mail - 22 January 2015





Mandurah Mail Mandurah WA 22 Jan 2015, by Amy Martin



General News, page 8 - 212.00 cm<sup>2</sup> Regional - circulation 37,375 (---T---)

PAGE 1 of 1



# Alzheimer's help

#### by Amy Martin

A NEW initiative is aiming to tackle the stigma and social isolation associat-ed with dementia through supporting the development of dementia-friendly communities communities.

Alzheimer's Australia Western Australia (AAWA) has invited those living with the disease and their carers to attend a community café on February 6 to talk about their experiences.

Local resident Helen Paul, whose hus-Local resident Helen Paul, whose hus-band Jim has dementia, said while the facilities available to them in Mandurah were fantastic, the event would be a learning experience and would give people an opportunity to when their environment voice their opinions.

"[Learning] anything new, anything helpful would be great," Mrs Paul said. "We haven't had a very long journey only fifteen months.

"When you're living with it, it feels

"But Alzheimer's [Australia] down here have been brilliant," Mrs Paul said.

"They help with outings; it's not just help for Jim but for me as well." There are about 30,700 people living

with dementia in WA and this number is expected to increase to almost 39,000 in less than 10 years.

The community café will act as a question and answer session and an open forum which will also allow those who attend to network with others in similar situations.

"The majority of people with demen-tia (approximately 70 per cent) live in the community and it is estimated that approximately 20 per cent [or 6140] live alone," AAWA chief executive Rhonda Parker said.

"Overwhelmingly the majority of those living with dementia live in their own homes in their community.

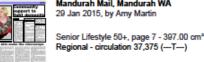
"We are asking those living with dementia to attend this community consultation and become a powerful voice that can really make a difference and will help AAWA create a dementia-friendly WA."

tia-tnendly WA. The community café will be at Ac-cent on February 6 from 2pm and will run for an hour and a half. Afternoon tea will be served throughout the ses-tion sion.

For more information or to register call Veronica Keltie on 9388 2800 or go to wa.fightdementia.org.au/com munity-café.

### Mandurah Mail - 29 January 2015





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Mandurah Mail, Mandurah WA 29 Jan 2015, by Amy Martin



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ID 366642342

PAGE 1 of 2

### Community support to fight de nen 'n

#### by Amy Martin

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Alzheimer's Australia Western Australia (AAWA) has invited those living with the disease and their carers to attend a community café on February 6 to talk about their experiences.

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"We haven't had a very

long journey – only fifteen months."

"When you're living with it, it feels longer," Mr Paul said. "But

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Afternoon tea will be served throughout the session.

For more information or to register call Veronica Keltie on 9388 2800 or go to wa.fightdementia.org.au/c om munity-café.

### North Coast Times Community, Perth – 27 January 2015



North Coast Times Community, Perth 27 Jan 2015, by Lucyjarvis

eneral News, page 4 - 292.00 cm<sup>a</sup> Suburban - circulation 14,319 (-T----)



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#### BUTLER

## Still making a contribution

#### RETIRED EDUCATORS SHARE EXPERIENCE OF LIVING WITH DEMENTIA

ALTHOUGH they have retired from careers in the education system, Glenda and Bronte Parkin continue to be educators. The Duncraig couple went into retire-

ment earlier than planned after Dr Parkin (51) was diagnosed with younger onset de-mentia and her husband became ber carer.

She had been the principal at a Perth private school and he had worked for the Education Department when her condition was diagnosed in 2010. Mr Parkin said concerns from his wife's

sister echoed his own that his wife was starting to struggle with perception for everyday tasks, particularly in unfamiliar surroundings

surroundings. Dr Perkin saw her CP, who referred her to a neurologist and after a few months of specialised tests was diagnosed with poste-rior cortical atrophy in October, 2010. Her form of dementia affects her visual

processing, so she can no longer recognise written words, handle money or see numbers on a phone keypad.

"I find it really quite hard – you can show me something, but I can't read," she said.

Her other symptoms include short-term memory loss and an inability to multi-task.

The diagnosis forced her to retire at 57, ending a 35-year career in education, and Mr Parkin stopped working a year later. He said their involvement in state and national committees for Alzbeimers groups helped them spread awareness about dementia. "It's because of that involvement that we have had that we cometimes appear a bit more across (dementia issues) than most people," he suid.

"Everyone has got a unique story about how they arrive at a diagnosts. "It's usually the people close to them

who notice the changes. "People should, even if they are older,

get a proper diagnosis because it may lead to better management." Mr Parkin said they hoped awareness

would lead to a more "dementia tolerant" community, including among employers. Dr Parkin said they had been guest speakers at CWA and other organisations'

speakers at CWA and other organisations events, sharing their story. "Most of my life I have been working and educating students," she said. "It just makes me feel as though I have still got something to contribute to the com-

munity, rather than just sit around and twiddle my thumbs."

Lucy Jarvis

### 6.6. Link to 2011 Access and Economics Report

https://fightdementia.org.au/sites/default/files/20100326-WA-AccessReportMar2010-Rpt-v1.pdf

### 6.7. Quotes from Workshops / Feedback Forms

### **Geraldton Dementia Friends Community Quotes**

"People often stop visiting once they know something is wrong."

"You don't think about it until it's in your world."

"Often friends stay away because they don't know how to deal with my parents."

"People don't realise that just visiting is ok. They don't have to have special skills, they aren't expected to entertain or hold a conversation."

"It's very hard to get my mother-in-law to go out into the community. She often refuses to go out. She has always been very fastidious about her appearance, now she needs a lot of prompting to do personal care. It may be a lack of confidence. I want to get her out as I know there's some great things out there for her to do but it's so hard to get her out."

"People need to be a lot more understanding. How you fare depends on who you are dealing with."

"To hopefully see a change in the community, to make it a more dementia-friendly community. To take into account everyone's concerns, to allow them to feel that their concerns are being listen to."

### Summary of Quotes from Café Feedback Forms

"I met a lovely couple and gained new information and inspiration!"

"Great opportunity to discuss with others".

"My experiences can be used to help others, so that is great."

"It was interesting to hear input from lots of different people."

"Very enjoyable, well-organised and social. There was a relaxed, yet professional feel to the event."

"Thank you so much – I appreciate events like this that help me/support me as a carer for my 90 year old grandmother."

"I was especially enlightening to know the first hand experiences of the carers & those with dementia."

"Helped greatly with my understanding of dementia (no previous knowledge)."

"Very useful talking with other carers for useful tips and other services available, and not feeling alone being a carer."

"Many points were discussed I had not given thought to previously."

"To hopefully see a change in the community, to make it a more dementia-friendly community. To take into account everyone's concerns, to allow them to feel that their concerns are being listen to."

"Very eye-opening."

"Learned much about the challenges of being a carer and the barriers in the community."



Alzheimer's Australia WA 55 Walters Drive Osborne Park WA 6017 08 9388 2800