

A GUIDE TO BECOMING A DEMENTIA-FRIENDLY COMMUNITY

REPORT, SEPTEMBER 2014

TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA
FIGHT DEMENTIA. ORG. AU

ACKNOWLEDGEMENTS

Alzheimer's Australia NSW gratefully acknowledges:

- People in the Port Macquarie region who are living with dementia, their families and friends who provided invaluable input and advice into the development of this Guide
- Mrs Leslie Williams MP, Member for Port Macquarie, for her commitment to and passion for supporting people living with dementia and their families
- Members of the Dementia-Friendly Community
 Port Macquarie Steering Committee
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- The general community of Port Macquarie
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Alzheimer's Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

This paper has been developed by the Policy, Research and Information Department, Alzheimer's Australia NSW. Paper authored by Judy Bartholomew and Brendan Moore.

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FOREWORD



Assisting people with dementia is part of the NSW Government's commitment to protecting the vulnerable. It is not only individuals but families, partners and friends who are affected by dementia. A growing number of people will become the primary carer of someone with dementia in the coming decades.

The NSW Government is committed to helping people with dementia live with dignity and to remain as connected to their communities for as long as possible. So I am delighted to introduce Alzheimer's Australia NSW's Guide to Becoming a Dementia Friendly Community.

Why is a dementia friendly community so important? Sadly we know that many people living with dementia and their families do not get a fair go. They face discrimination and social stigma instead of feeling supported and understood.

For this reason, it is timely that we now see the production of such an excellent resource, containing helpful advice to those who want to make their community more dementia friendly.

The Hon John Ajaka MLC NSW Minister for Ageing



FOREWORD



Why is Becoming A Dementia-Friendly Community Important?

Imagine if you woke up tomorrow and were told you had a diagnosis of dementia. How would you like people to view you? Would you like to still be included in your local community or told you could not participate anymore? How would you feel to be ignored, lose friends, and be treated with disrespect? Would this be giving you and your family a fair go? This has been my experience and many others have told me they have had similar experiences.

Our quality of life is really influenced by a sense of self-worth and by being connected with the community, but the stigma associated with dementia can lead to loneliness and feeling that we aren't welcome anymore. Other people living with dementia have said things like 'the doctor just ignored me', and a carer said 'I've seen a shop assistant roll her eyes just because we needed a little more time'. We become worried about telling people that we have dementia, because we are often afraid of what their reaction will be.

The physical environment and the design of buildings can also make it difficult to access shops, health services, businesses and recreational areas. Simple things like clear signage to where public toilets are would really help us find our way around.

Feedback from people with dementia and their carers tell us that the barriers to a dementia-friendly community can be grouped into:

- Physical environments poor signage, lack of seating in public areas and unhelpful public transport staff
- Social environments and inclusiveness business and services staff who are not helpful, and negative community attitudes.
- Health and community support health staff not knowing about dementia and treating people with disrespect.

By creating more dementia-friendly communities, these barriers can be reduced or removed completely, which will allow people living with dementia like me, to continue to enjoy a meaningful and fulfilling life. This will benefit not only people living with dementia and their families, but also the community as a whole.

'Can communities be dementia-friendly? Let's make sure that they are.

With a little thought towns' folk can be taught that a simple idea can spread far.'

From the chorus of one of my latest songs about dementia, 'Dementia-Friendly Communities'

Graeme Atkins

PURPOSE OF THE GUIDE



The purpose of this Guide is to support local organisations, groups and individuals who want to make their community more dementia-friendly. The Guide is for people who want to make a positive difference to, and work with, people with dementia and their families including:

- Elected officials Federal and State members and Local Government Councillors
- Local Councils
- Government Departments and services
- Health and aged care providers
- Community organisations
- Businesses and work places
- Retail outlets
- Sports clubs
- Social clubs
- Individuals who want to make a difference but don't know where to start.

This Guide provides a practical framework based on a change management approach of eight steps to assist communities in working towards becoming more dementia-friendly.

It is not meant to be prescriptive or exhaustive in describing what to do to become more dementiafriendly, as each local community is unique and will be at different stages.

The Guide is informed by work carried out overseas and from across Australia. The process and activities being undertaken in the Port Macquarie region of New South Wales are used as a case study throughout the Guide to demonstrate how the community there is following a change management approach to make it dementia-friendly.

'... there is still a very long way to go before people with dementia are no longer discriminated against, and before we achieve a global dementia-friendly society'

Christine Bryden website: www.Christinebryden.com

'So when are you going to go mad?' (comment made to a person with younger onset dementia)

'People talk down to me'

(comment made by a man recently diagnosed with dementia).

WHAT IS A DEMENTIAFRIENDLY COMMUNITY?



Under the Universal Declaration of Human Rights, the purpose of the UN Convention on the Rights of Persons with Disabilities is to:

'Promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'

'Throughout history, persons with disabilities have been viewed as individuals who require societal protection and evoke sympathy rather than respect. This convention is a major step toward changing the perception of disability and ensures that societies recognize that all people must be provided with the opportunities to live life to their fullest potential, whatever that may be.'

Whilst the convention is a major step forward, and legislative changes have assisted people with physical disabilities to access the community, practical applications for people living with dementia and cognitive disabilities are not as well advanced.

A dementia-friendly community can be described as:

'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives'

(Alzheimer's Society, 2013).

People living with dementia and their families in Port Macquarie describe dementia-friendly as:

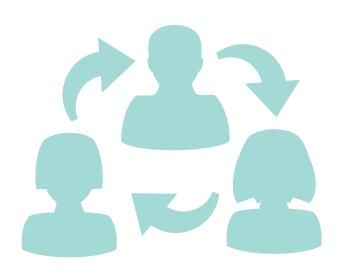
- A community where people are dementia aware, therefore helping to reduce stigma and myths
- Health staff are educated about dementia and treat people with respect and empathy
- Retail and café staff know about dementia and are helpful and have a caring attitude – basically good customer service
- The physical environment enables people to get out and about safely
- Support services are helpful and enabling
- People living with dementia feel like they still belong to the community, their social networks, their clubs, and importantly have a role to play.

A community that is dementia-friendly is one that people living with dementia and their families say is dementia-friendly. They are after all the experts in what works and does not work for them. It is a community supportive of the individual needs of people with dementia. It has people living with dementia at the centre of its strategies and it puts in place actions to become more dementia-friendly. It's a community that gives people living with dementia a fair go and embraces the adage "nothing about me without me".

'The staff at the café are wonderful, they are really understanding and aren't phased by any 'odd' behaviour. We feel very comfortable and welcome there.'

(comment from a carer).

WHY ARE WE USING A CHANGE MANAGEMENT APPROACH TO THIS GUIDE?



Creating change within communities is not something that governments can do alone. Rather, it is an ongoing process based on a social movement, which includes at its heart the priorities for action as stipulated by people with dementia and their families living in the local area. A whole of community approach also requires a change of cultural attitudes if the stigma and fear of dementia is to be changed to an environment characterised by understanding, acceptance and social inclusion

(Alzheimer's Australia, 2013).

'Our friends don't visit anymore' (comment by a carer)

'I've seen people I know cross the street to avoid talking to him'

(comment from a carer)

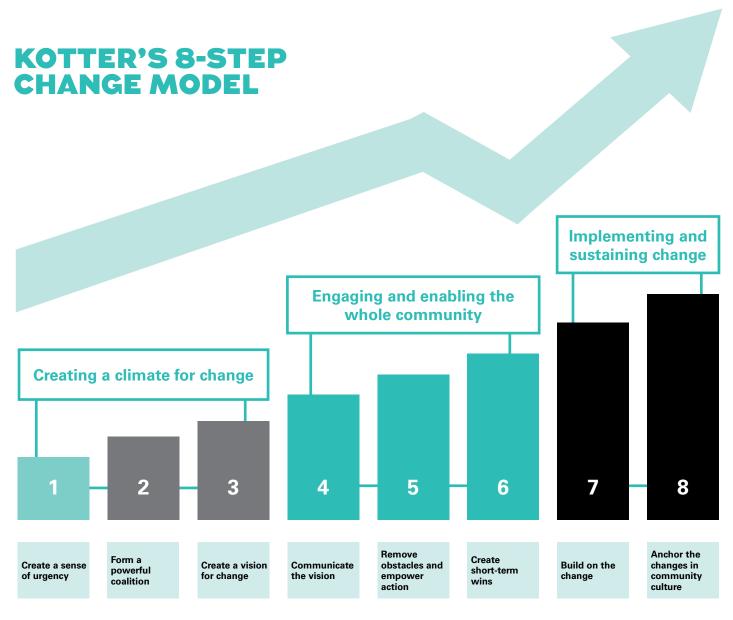
A change management framework provides a simplified and logical approach to not only change the perceptions of individuals, but the community as a whole. This Guide uses an 8-step change model (Kotter, 1995) as the overarching framework to provide readers with a practical and easy to follow template to facilitate the creation of a dementia-friendly community in their local areas. It also draws on a theory of change which suggests providing guidance and direction to people's rational side, whilst also appealing to factors which motivate their emotions (Heath C. and D., 2010). The Port Macquarie experience focuses on a whole of

community approach, however, individual organisations and services can also use the 8-steps approach to become more dementia-friendly.

Creating a more dementia-friendly community is not something that happens overnight. Remember how long it took to change community attitudes towards cancer, which went from an illness that was never talked about to now being one that is constantly in the public domain and treated with compassion and understanding. It is by changing one thing at a time that we can also begin to make a real difference to the lives of people living with dementia and their families.

Whilst not exhaustive, the references and further reading section of this Guide provide information about a range of resources, papers and initiatives that contribute to making local communities more dementia-friendly if the reader would like to learn more.

STEPS TO CREATE A DEMENTIA-FRIENDLY COMMUNITY



STEP 1: CREATE A SENSE OF URGENCY



Fostering a feeling of urgency is the first and most critical step in a successful change effort as this will trigger the initial motivation to get things moving. For change to happen you need the community or organisation to want it to happen and to be motivated. Without this, people won't get involved and change will not occur.

What can you do?

- Obtain the statistics on dementia for your local area, identify the trends, such as the increasing numbers of people with dementia in the community
- Start honest discussions Meet with local politicians, community leaders and get people talking. Include people living with dementia and their families and carers
- Put it on the agenda for your next staff meeting
- Create a story around the issues facing people living with dementia and their families on a daily basis
- Request help from other stakeholders.

What result do you want to see?

 People start talking about it and saying "Let's do it, we need to change things!"

THE PORT MACQUARIE EXPERIENCE

Port Macquarie has the third highest prevalence rates of dementia in NSW. The rapidly growing numbers of people living with dementia was recognised by local service providers and the MP for the NSW state electorate as a major issue, both socially and economically.

From this initial small group of committed people, the concept of creating a more dementia-friendly community was formed.

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

STEP 2: FORM A POWERFUL COALITION -BUILD A TEAM



The Port Macquarie Steering Committee

To lead change you need to bring the right people together who are fully committed to dementia-friendly communities. A diverse group made up of individuals at all levels and with different skills who are well-respected within the local community and have power and influence to make change happen constitutes a good team.

What can you do?

- Identify an individual who can take the leadership role, for example a prominent figure in the local community
- Identify other leaders from across the community who could be involved use your networks
- Ensure as a priority you speak to people living with dementia and their carers and include them in the team
- Bring people together arrange a meeting to discuss the concept of dementia-friendly communities and the reasons why change is needed. Share the sense of urgency
- Use the media to promote the formation of the team.

What result do you want to see?

• A strong team of diverse individuals with the necessary expertise and influence to guide change is established.

THE PORT MACQUARIE EXPERIENCE

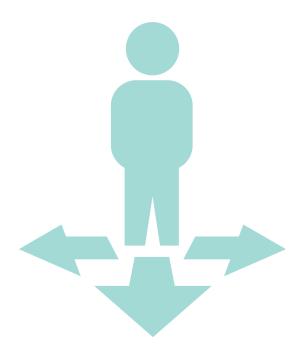
A strong Steering Committee was formed comprising: people living with dementia, family carers, representatives from the Local Council, service clubs, the Education Department, emergency services, aged care providers, the Local Health District, church groups, Alzheimer's Australia NSW, and other interested community representatives.

The group was led and chaired by Mrs Leslie Williams MP, State Member for Port Macquarie, with assistance from the local Alzheimer's Australia NSW Office. Mrs Williams also visited the United Kingdom to study a number of emerging dementia-friendly communities, thereby increasing the knowledge base and passion of the entire team

The media was again used to promote the formation of this Steering Committee.

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STEP 3: CREATE A VISION FOR CHANGE



A clear and sound vision is essential in ensuring that everyone involved understands what is trying to be achieved. A clear vision can help link individual projects and activities into the broader objectives for the community.

It is vital that people living with dementia and their families are involved at the local level in helping the team understand what being dementia friendly means in their community. This includes supporting pre-diagnosis life activities and interests and people with dementia having clear pathways for future opportunities.

What can you do?

- Talk with people living with dementia and their families about what they see is working well in the local area and what areas could be made more dementia-friendly – feed this information into the team's planning
- Develop the values that will underpin any changes and ensure all team members can clearly articulate these
- Include a draft Terms of Reference at the initial team meeting for the members consideration and agreement
- Draft a work plan so members are clear about projects that fit with the vision and who is responsible for progressing actions
- Be clear about expectations what are realistic goals?
 It is important to strike a balance between what is desirable with what is feasible and achievable.

What result do you want to see?

• A clear vision, which is informed by people living with dementia and their families, is articulated and made central to all future planning.

THE PORT MACQUARIE EXPERIENCE

Focus groups for people living with dementia and their families were held in Port Macquarie to gain input into what a dementia-friendly community might look like. Information about what was seen as working well in the local area was collected, as well as what areas needed improvement. This information was presented to the Steering Committee members.

A draft Terms of Reference was provided to the Steering Committee members for comments and agreement. Wording around the vision included: 'dementia-friendly communities focus on improving the community inclusion and quality of life for people living with dementia.'

In a dementia-friendly community people:

- will be aware of and understand more about dementia
- living with dementia and their carers will be encouraged to seek help and support
- living with dementia will feel included in their community
- living with dementia will have more choice and control over their lives.

A work plan was also developed to capture strategies and projects and ensure they fit with the vision and priorities articulated by the people living with dementia and their families in the focus groups.

Media promotion of the focus groups further highlighted the work undertaken and drew attention to the issue.

STEP 4: COMMUNICATE THE VISION



There is little point in having a clear vision if no one knows about it.

'Without credible communication, and lots of it, the hearts and minds of the troops are never captured'

(Kotter, 1995, pg 63).

Clear and ongoing communication both within the team and the general community is critical if change is to be made. Leading by example is also an essential element of communicating and implementing the vision.

What can you do?

- Use the media and other communication channels at every opportunity to communicate the vision and the work being undertaken
- Use high profile people and community leaders as spokespeople, to enhance credibility. People with dementia as spokespeople will further enhance the validity of statements made in the various communication channels
- Include the stories and support from people living with dementia and their families to also enhance the sense of urgency
- Ensure the team members continue to communicate and engage with their own industries, groups and organisations, and to lead by example through project implementation and enthusiasm.

What result to do want to see?

 The local dementia-friendly community vision is communicated to the community and throughout organisations on an ongoing basis, using credible sources and through the actions and examples of community leaders.

THE PORT MACQUARIE EXPERIENCE

People with dementia and their families shared their stories with the print media.

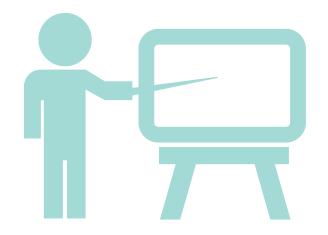
The local State MP and the Alzheimer's Australia NSW office provided media releases and articles to the local media on an ongoing basis to promote the dementia-friendly concept and raise awareness.

Mrs Williams, as the local MP also used her community newsletters to continually inform the local community about the progress of the dementia-friendly community project, again creating credibility for the actions. Mrs Williams also spoke with her Federal counterpart and shared the vision for Port Macquarie with them.

Steering Committee members talked to their organisations to tell them about the initiative. The Steering Committee developed a meeting schedule, circulated minutes and developed meeting agendas well before meetings took place.

A presentation was given at a local regional conference and the Port Macquarie initiative highlighted within NSW and nationally.

STEP 5: REMOVE OBSTACLES AND EMPOWER ACTION



Sometimes barriers or perceived barriers to change may arise. Most commonly these might be articulated around time or capacity restraints to implement changes, or difficulties in changing the attitudes of others. In the early stages, it is very unlikely that all obstacles can be removed and some may never be overcome. However, by empowering those who can make changes to take action, many of these obstacles can be overcome in time.

What can you do?

- Use the team to identify potential barriers, either individuals or structures and assign priority to those of greatest risk
- Use the collective knowledge and influence of the team to remove or reduce the barriers through positive actions and strategies
- Recognise and publically reward those who are making changes happen
- Use what is happening already as examples of what can be done
- Pursue funding applications through a range of agencies, foundations, trusts, local philanthropists, businesses who may support small to medium size activities and projects that remove real or perceived barriers.

What result do you want to see?

• Effective actions and strategies are put in place to help reduce or remove obstacles to creating a more dementia-friendly community.

THE PORT MACQUARIE EXPERIENCE

One strategy agreed by the Steering Committee members was to publicise the 'Is It Dementia' education resource to local businesses so that staff could be made more dementia aware.

The obstacle identified was the significant time for the information to be personally provided to the many organisations and businesses in Port Macquarie.

After further discussions, the obstacle was reduced significantly through the use of various organisations' volunteers and students, and by a commitment by Steering Committee members to spread the information through their other networks and industry forums.

Applied for and was successful in obtaining NSW Clubs Grants funding to support activities on the work plan.

STEP 6: CREATE SHORT-TERM WINS



As previously stated, real change and transformation takes time. Without some short terms wins and achievements, there is a very real risk of losing momentum, and the sense of urgency will be replaced by one of disappointment and discouragement. This may result in the team breaking up and the vision remaining unrealised.

Short-term wins will motivate and re-energise the team and the general community, but most importantly it will demonstrate that change is happening and quality of life improvements are being realised for people living with dementia and their families. It will show people you mean what you say.

What can you do?

- Include short-term, small, easy to do and 'realistic' projects in your planning process as well as longer-term goals
- Make sure these are in line with the priorities local people living with dementia and their families have articulated and agreed with
- Make sure these wins and achievements are celebrated by the team and publicised to the local community. Include how others can also follow this example which furthers community buy-in to your vision
- Stress the simplicity and ease of the project's implementation and most importantly the benefit derived by people living with dementia and their families
- Ask people living with dementia about the improvement and document these comments to help monitor and evaluate the success of the initiative
- Monitoring these wins will help evaluate their success, or find ways it could have been done better.

What result do you want to see?

 Small but effective short-term projects, in line with the wishes of local people with dementia and their families have been successfully implemented, celebrated and communicated to the community.

THE PORT MACQUARIE EXPERIENCE

One of the Steering Committee members commented that helping to create more dementia-friendly communities was very do-able using small steps. It's also about taking every opportunity to increase awareness.

One example was that a sub-committee, which included people living with dementia and their families, developed a submission to the Local Council's Draft Town Green Masterplan and the Town Square Masterplan. The submission included the need for: additional seating with backs and arm rests; shaded areas; quieter, small areas; wide, even, seamless footpaths; colour contrast toilet doors to the toilet wall; a large 'old fashion' clock in a prominent position which included the time and date; clear signage for parking, toilets and pathway destinations.

The use of colour contrast for the public toilet facility at Bonnie Hills was also an achievement celebrated by the Steering Committee and people with dementia.

A local café is being very supportive by including talks to staff from a person living with dementia and forming a partnership with a local church to help fund practical equipment, such as mugs with two handles.

The Steering Committee also noted that there were already projects underway which were increasing the dementia friendliness of the region including:

- The annual AlzNSW Memory Walk & Jog to raise awareness
- The Glasshouse Art Appreciation project
- The Creative Connections Art Program and annual exhibition
- Training volunteers to run community awareness session to the broader community and also to use their own network of service clubs and sporting groups to increase knowledge and awareness
- The increase in awareness of the 'Safely Home' Program amongst local police officers by the police force representative.

STEP 7: BUILD ON THE CHANGE -DON'T LET UP



The quick wins are only the beginning of implementing lasting change. Whilst celebrating these achievements is important, announcing that 'we have now become dementia-friendly' runs the real risk of slowing or stopping momentum and people thinking that everything that can be done has been done. Real changes take time.

To keep moving forward, the short term wins can be built upon as steps towards the broader vision. One success can lead to another, and then another. Ongoing success will keep the Steering Committee members motivated and bring in new stakeholders interested in your success.

What can you do?

- Look at every successful action/project to see what went right and what needs improving
- Look at your short term wins and see how these can be expanded (stretch goals)
- Set new goals to keep the momentum going
- Continuously check with people living with dementia and their carers on priorities for change and for new ideas. Include people you may not have spoken to previously
- Check if there are other community members and leaders who could bring fresh ideas to the team.
- Look at other communities to see what actions they have implemented that you have not tried yet.

What result do you want to see?

An ongoing expansion of successful and new projects is occurring in line with the priorities expressed by people living with dementia and their families.

THE PORT MACQUARIE EXPERIENCE

Some examples of building on successful projects included:

The implementation of the Men's Shed project in the Hunter region of NSW was expanded to include Men's Sheds in the Port Macquarie region.

Dementia awareness information sessions were provided to Local Council staff and also to volunteers who could then run dementia awareness sessions to the broader community and to their own social groups and club networks. This way awareness can be spread further.

STEP 8: ANCHOR THE CHANGES IN COMMUNITY CULTURE



The final step is to ensure the change becomes 'the norm'.

What can you do?

- Talk about the progress and continue promoting the successes in a range of formats
- Team members can embed the dementia-friendly principles into their own organisations and staff training
- Ensure original members and change leaders continue to be recognised for their achievements and contributions
- Ensure there is a system in place to replace key change leaders if they leave
- Ensure records are kept so that information is not lost
- Keep talking to people living with dementia and their families in the local area, including those not previously spoken with.

What result do you want to see?

 People living with dementia and their families have an increased quality of life through increased social inclusion, increased feelings of self-worth and improved health and support services.

THE PORT MACQUARIE EXPERIENCE

Port Macquarie is still in the early stages of moving towards becoming a dementia-friendly community.

Dementia awareness is becoming part of the Steering Committee members 'core business' and is being embedded in the various organisations' consciousness though continued discussion and media coverage.

Over the next few years, in line with the longer term plans, it is hoped that the final result will be closer to realisation. However, it is understood that the work will never really stop as you cannot reach a finite state of 'being', you are always 'becoming' dementia-friendly.

MAKING NEWS



Clear case for design

AT the most recent meeting of the Dementia Friendly Steering Committee members agreed that they should make a submission to the Port Macquarie-Hastings Council's draft Town Green and Town Square Master Plans.

Steering committee chairwoman Leslie Williams said with Port Macquarie having the second highest prevalence of dementia per capita in New South Wales it was vital that people living with dementia remained engaged in the local community.

She said the committee believed it was important that we planned now to future-proof our communities so they could be accessible to the needs of an ageing population.

"It is important that the Port Macquarie-Hastings Council plays an integral role in the development of the first dementia-friendly community in Australia," Ms Williams said.

"By adding improvements to the design of new projects such as those planned for the Town Square and Town Green we can ensure that people living with dementia can take advantage of community facilities like everybody else."

The steering committee has made a submission to the draft Town Green and Town Square Master Plans which focusses on age-friendly and dementia-friendly seating, walkways, toilets and signage.

Regional manager of Alzheimer's Australia NSW Gary Thomas, who is also a member of the steering committee, said that people living with dementia experienced symptoms including alteration to memory, disorientation and depth perception changes, so it was important that pathways were clearly defined providing a sense of safety and that this was complemented by appropriate and well-placed seating.

"The committee supports wide walkways with plenty of seating along the paths as well as seating with backrests and arms so that there is an easy transfer from sitting to standing," Mr Thomas said.

"It is also important that signage in public areas is in large print and legible and that universal symbols are used to identify facilities such as toilets.

"The development of the master plans for these public spaces highlights just how the community can work together to ensure a more inclusive environment."

Dementia-friendly vision takes shape

A STEERING committee wants to hear the views of people living with dementia or their careers in a step towards making our area the first dementia-friendly community in the nation.

The recently formed Dementia Friendly Steering Committee adopted a series of measures late last year to make the Port Macquarie-Hastings the first dementia friendly community in Australia.

The state electorate area of Port Macquarie ranks second out of 93 electorates in the state for the highest prevalence of dementia.

Port Macquarie MP and committee chair Leslie Williams said one issue the committee adopted was to ask members of the community living with dementia or their carers exactly what they thought could be done to make the idea become a reality.

"The committee feels the

best way to start this project is to ask those people who are living with dementia every day what they would like a dementia friendly community to look like," she said.

A series of workshops will bring people with dementia and their carers together to discuss options.

"If anyone is living with dementia or caring for someone who has dementia, we would love to hear from them about how we can make the Port Macquarie region more supportive of people with dementia and their carers," Mrs Williams said.

"At the same time, Alzheimer's Australia NSW which is the peak body for people with dementia, their families and carers is developing a guide for local communities on how to become more dementia friendly."

"This will provide ways on how the community can work together to ensure a more inclusive environment."

Mrs Williams said people might have already found some things in the community which worked well but there could be areas that could do with improvement.

"We would like people to share their views and experience with us at one of the proposed meetings," Mrs Williams said.

HAVE YOUR SAY

Meetings will be held at the Mid North Coast Medicare Local's Port Macquarie office at 53 Lord Street on February 17 from 10am until noon or February 21 from 10am until noon or 2pm until 4pm.

It is important to book by calling Terri Cane on 66584 7444. Call Judy Bartholomew on

6651 6415 or email judy.bartholomew@ alzheimers.org.au for further information.

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© Port Macquarie Independent, 8 May 2014, page 13

NBN GOLD COAST, NBN NEWS 16 JAN 2014 06:11PM

THE PORT MACQUARIE AND HASTINGS REGION IS TRYING TO MAKE THE AREA THE NATION'S FIRST DEMENTIA-FRIENDLY COMMUNITY. A SERIES OF WORKSHOPS, BRINGING PEOPLE WITH DEMENTIA AND THEIR CARERS TOGETHER, WILL BE HELD NEXT MONTH AT THE MID NORTH COAST MEDICARE OFFICE IN PORT.

(iSentia summary)

ABC COFFS COAST, COFFS HARBOUR, 08:30 NEWS, NEWSREADER 15 JAN 2014 08:31AM

STEPS ARE UNDERWAY TO TRANSFORM PORT MACQUARIE-HASTINGS INTO A DEMENTIA-FRIENDLY COMMUNITY. JUDY BARTHOLOMEW, ALZHEIMER'S AUSTRALIA, WILL SIT ON A LOCAL COMMITTEE THAT WILL HOLD WORKSHOPS TO GET INPUT ABOUT WHAT A DEMENTIA-FRIENDLY COMMUNITY MIGHT LOOK LIKE.

Judy Bartholomew, Alzheimer's Australia NSW (iSentia summary)

Workshop invitation

ALZHEIMER'S Australia is working to develop dementia-friendly communities and organisations in Australia to tackle the stigma and social isolation which can be associated with a diagnosis of dementia.

People with dementia, carers, service providers, businesses, and local government representatives are invited to participate in an interactive workshop on dementia friendly communities facilitated by UK dementia expert Rachael Litherland.

Rachael Litherland has worked in the UK with people with dementia for the past 15 years. With a background in psychology and advocacy, she developed and managed the national "Living with Dementia" programme for the

The workshop will be held on Friday, April 4, at Rydges Port Macquarie in Hay St.

You can RSVP before Friday, March 29, via NSW.midnorthcoast@alzhe imers.org.au or by phoning 6584 7444.

Dementia spotlight

WHEN the regional conference of the Australian Association of Gerontology and The Aged and Community Services Association of NSW & ACT opens this morning at the Glasshouse, it will be a significant moment for Port Macquarie.

The state electorate has the second highest prevalence of dementia sufferers in NSW, making the conference an important marker in Port Macquarie's journey to become a dementia-friendly community. Alzheimer's Australia's Gary Thomas is the organisation's regional manager for the north coast.

He praised the persistence of Port Macquarie-Hastings Council and the Hastings Macleay Dementia Action Group in securing the event.

Mr Thomas said the conference, along with a visit in April by British dementia expert Rachael Litherland, continues the town's commitment to tackling the stigma and social isolation associated with a diagnosis of dementia.

"What we want to do is make

sure people with dementia, and their carers and family, are included," he said.

"We want them to be accepted, regardless of their cognitive ability."

The conference welcomes health and aged care practitioners, researchers, community carers and anyone interested in current issues in ageing.

A conference spokeswoman said key concerns such as achieving better outcomes for lower cost, as well as who pays the hidden costs of improving government services, will be discussed.

It has been a busy year so far for dementia care and research in the Hastings.

April's Alzheimer's Australia workshops led by Ms Litherland will follow extensive community consultation over the last two months, Mr Thomas said.

The north coast branch of Alzheimer's Australia conducted workshops throughout February with carers. These were invaluable for airing concerns and determining the best ways to use future funding, Mr Thomas said.

The input of carers is helping the steering committee develop a work plan to be presented to the state government during September's mental health awareness week, Mr Thomas said. "We've been getting a really good cross-section of people and ideas," he said.

"Growing those ideas, especially for something simple like creating larger text for signs, is really important."

The session at Rydges in Port Macquarie on April 4 will be the only stop in NSW by Ms Litherland during her national

AAG and ACS Regional Conference

Sharing Care for Older
Australians: Working Together
Today and tomorrow, the
Glasshouse, 8.30am.
Dementia-friendly communities:
involving people with dementia.
Presented by Rachael Litherland
April 4, Rydges Port Macquarie,
10am.
RSVP: March 29, to

RSVP: March 29, to midnorthcoast@alzheimers.org.a u or 6584 7444

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OTHER EXAMPLES FROM WITHIN AUSTRALIA AND OVERSEAS

There are many other examples of projects from within Australia and overseas, particularly the UK, including:

- Use of the Alzheimer's Australia NSW Memory Van at community events across NSW to help raise awareness.
- The Men's Shed integration project started by Alzheimer's Australia NSW in the Hunter region of NSW.
- Exercise groups for people living with dementia in Healthy Ageing Centres in Sydney
- Museum of Contemporary Art and Sydney BIENNALE activities that involve people with dementia – as participants or attendees
- The Dementia Action Alliance groups being set up in the United Kingdom (UK)
- The 'Dementia without Walls' project in York, United Kingdom
- Training of retail and service provider staff in York to become more aware of the needs of people living with dementia
- Training of library staff in various locations across Australia
- Training volunteers to help run dementia awareness information sessions
- Training over 4 million volunteers to engage with people with dementia in Japan
- The Working in Schools DVD production project in York
- The Bunnings project in South Australia which is helping people living with dementia continue working.

'He needs to feel he still belongs'

(comment from a carer)

CONCLUDING STATEMENT

Becoming more dementia-friendly does not have to be difficult. Small changes to the built environment such as clear signage and colour contrast for doors and walls in toilet facilities can be easily and cheaply achieved.

However, it is the attitude of staff and the general community that really makes the difference to a community, organisation or small social group becoming more dementia-friendly.

The Port Macquarie experience has shown that having that sense of urgency and strong and passionate leadership is important in gaining community support and commitment. It has also demonstrated that the advice from people living with dementia and their families, and the sharing of their stories is critical to the creation of a vision that makes a real difference to enhancing their lives.

The use of media to raise awareness in the general community as well as using internal communication channels within organisations, businesses and services is also an important element in reducing the stigma around dementia. Working around perceived or real obstacles and celebrating short term wins keeps the momentum going, but more importantly increases the quality of life for people living with dementia and their families.

Building on successes can be as simple as expanding a successful program to another part of the community or implementing a project which has been working elsewhere. It is about always listening to people living with dementia in your local community to make sure you are on track and that the projects have been successful.

'The most general lesson to be learned from the more successful cases (of change) is that the change process goes through a series of phases that, in total, usually require a considerable length of time. Skipping steps creates only the allusion of speed and never produces a satisfying result.' (Kotter 1995, p. 59)

Lasting change does take time, but anything as important and worthwhile as upholding the rights of all Australians living with dementia and their families, giving them a fair go, must surely be worth all of us making the effort.

The Hon. John WatkinsCEO Alzheimer's Australia NSW

John Watkin

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To find out more about dementia-friendly communities, please visit Alzheimer's Australia website:

WWW.DEMENTIAFRIENDLY.ORG.AU

Visit the Alzheimer's Australia website at

WWW.FIGHTDEMENTIA.ORG.AU

Or for information and advice contact:

NATIONAL DEMENTIA HELPLINE 1800 100 500

The National Dementia Helpline is an initiative of the Australian Government



A dementia-friendly community can be described as:

'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives' (Alzheimer's Society, 2013).