Kiama pilot project leads the way

Lyn Phillipson and Glenn Rees discuss a new project launched in Kiama, NSW, which has the potential to change the way people with dementia in Australia interact with their social and physical environments.

A diagnosis of dementia often brings with it social isolation, stigma and discrimination. Alzheimer’s Australia is working to tackle these issues through helping to create dementia-friendly communities.

At the heart of this initiative is the recognition that people with dementia want to participate in everyday activities, and are able to do so with the support and understanding of their communities. Just like any other Australian, people with dementia want to have meaning and purpose in their lives.

Alzheimer’s Australia has begun a pilot project in Kiama to test approaches for developing dementia-friendly communities in collaboration with people living with dementia, the Kiama Council and the University of Wollongong. The dementia-friendly community pilot project will see Kiama become one of the first dementia-friendly communities in Australia and will help kick-start more initiatives to build a dementia-friendly Australia.

The project aims

It is still early days in the development of this pilot program and the direction will depend in large part on the feedback from people with dementia. The aim is to achieve:

• Increased community awareness and understanding of dementia.
• Increased opportunities for social engagement for people with dementia.
• Assistance for people with younger onset dementia to remain employed.
• Assistance for people with dementia to get involved with volunteering.
• Piloting the development of dementia-friendly organisations within five local organisations.
• Improvements to the physical environment in the community to improve wayfinding and reduce stress. The views of people living with dementia will be central to the development of the dementia-friendly program in Kiama. There are a number of ways this will be achieved:

• One-on-one interviews to gather information about what life is like for people with dementia in the community, including identifying the things that work well in Kiama, as well as providing advice on what could be improved to support people to live well.
• Local people with dementia ‘walking communities.

Benefits for all

Across the many miles I travelled and the many conversations I had it became abundantly clear that the beneficiaries of this movement to develop dementia-friendly communities was widespread – from people living with dementia to their carers, to each and every person and every organisation who chooses to be meshed in this transformation of local communities.

For more information about the Port Macquarie Dementia-Friendly Steering Committee and project, contact Alzheimer’s Australia (NSW) Port Macquarie Dementia and Memory Community Centre on (02) 6584 174 444.

Leslie Williams is the Member for Port Macquarie, Chair of the Port Macquarie Dementia-Friendly Steering Committee and convenes the NSW Parliamentary Friends of Dementia Group.

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Kiama’s dementia-friendly communities pilot project will involve many individuals and organisations, including local resident Helen Webb (front right) who is living with dementia, her husband and carer Jim Webb (front left), Kiama Council’s Community and Cultural Development Manager Nick Guggisberg and council’s Community and Cultural Development Director Clare Rogers

Photo: Kiama Municipal Council

committee recently made a submission to the Port Macquarie-Hastings Council inviting it to carefully consider those with dementia when planning new and upgraded public assets and spaces such as the Town Square and the Town Green. Julie Priest is our council’s Community Development Officer: Aged and Disability and we are fortunate to have such an active and motivated representative on our committee. Her passion will ensure we take every opportunity to participate in decisions about local infrastructure to ensure it is appropriate for our ageing community, including those living with dementia.

One of the focuses of the steering committee is to engage with the business community because it cannot be overstated the important role it can play in supporting people living with dementia and their carers by being accessible and accommodating. The enthusiasm of one local café, that we envisage will become a model of a dementia-friendly business for Port Macquarie, is exciting.

Through this pilot we aim to develop a checklist verifying staff from local businesses are educated and understand the needs and challenges facing people living with dementia in our community. Central to the process for change will be the engagement with local people living with dementia and their carers to identify and address issues relating to the physical environment of local businesses, such as access, noise and furnishings.

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the patch’ with staff from the University of Wollongong to share local knowledge about the places people with dementia access and enjoy and the places they avoid or feel excluded from. Mapping software will then be used to interpret this information to highlight any commonalities or gaps in local services or infrastructure.

- Membership of people with dementia on a Local Dementia Alliance that will guide the program.

**Community involvement**

Alzheimer’s Australia will also seek community feedback through a broader community forum which will be held in September during Dementia Awareness Month. This forum will include presentations by people with dementia about their experiences living in Kiama, presentations by researchers on their findings to date, as well as a keynote presentation from Stephen Milton, a UK-based dementia-friendly expert. Stephen will talk about the work in the UK on dementia-friendly communities and share the lessons and experiences to date from that journey (see the article by Stephen Milton and Rachael Litherland about this work, on p20).

A Local Dementia Alliance will be established, made up of people with dementia, family carers and representatives from community organisations. This alliance will use the feedback from people with dementia, as well as the broader community, to develop an action plan for Kiama which will set out short-, medium- and long-term goals for the community in the process of becoming dementia friendly. The Local Dementia Alliance will provide ongoing advice on the roll-out of the program as well as identify additional opportunities in the local community.

An essential component of the community pilot is working with local organisations to ensure their services meet the needs of people with dementia. Banking, buying groceries, paying a bill and posting letters are some of the everyday tasks that people with dementia want to continue doing, and often with the appropriate support they can. Alzheimer’s Australia will pilot a recognition process for organisations that commit to working towards becoming dementia friendly.

This process will require organisations to develop an action plan against specific principles such as staff awareness, physical design and communication. These plans will be assessed by the Local Dementia Alliance and organisations will be provided with a symbol to denote that they are working towards becoming dementia friendly. This approach will be piloted first in Kiama, with the goal of a broader roll-out across Australia.

**Testing ground**

The dementia-friendly pilot in Kiama will provide a testing ground for a range of innovative initiatives to address social inclusion, physical design and understanding of dementia, including small grants to community organisations to promote involvement of people with dementia, engagement with schools, development of resources and tools such as an audit tool for physical design of public spaces and community education.

The Kiama pilot will provide an opportunity to monitor and evaluate the development of the dementia-friendly initiative and Alzheimer’s Australia is working in partnership with the Global Challenges Program at the University of Wollongong (http://bit.ly/1beH7vL) to monitor the progress of this initiative and ensure that the lessons learned in Kiama are shared to support more communities to become dementia-friendly. This will be achieved through the development of an online dementia-friendly toolkit with useful resources and checklists.

The Alzheimer’s Australia, Kiama Council and University of Wollongong partnership, along with the Kiama Local Dementia Alliance, are committed to continuing to work with people living with dementia in Kiama to achieve a dementia-friendly community. This initiative presents huge opportunities for not only the Kiama community but for all Australian communities as the prevalence of dementia increases. We need to continue to act to ensure all Australians with dementia live in an accepting and inclusive community that supports, understands and encourages people to live well with dementia.

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Kiama, on NSW’s South Coast, is the site for a dementia-friendly community pilot project.