About the Research Project

The University of Wollongong, in conjunction with Alzheimer’s Australia and Kiama Municipal Council conducted research from September - December 2014 to understand what it’s like to live in Kiama with dementia.

Research activities included:

- interviews and mapping activities with a total of 23 people including local people with dementia and their supporters
- the development and testing of a tool to audit places and spaces in Kiama that are frequented by people living with dementia
- a survey of 123 local community members about their knowledge of and attitudes towards dementia
- a survey of 22 organisations that service people living with dementia in Kiama.

These activities helped to identify features of the physical, social and service environments which help or hinder the experiences of people living with dementia in Kiama. The following sections provide an overview of the findings for research participants and members of the public with an interest in the Dementia Friendly Kiama Pilot Project.

What is it like to live in the Kiama area with dementia?

Overall, people with dementia found the Kiama area to be a good place to live given the beautiful natural environment, the ‘village’ atmosphere, and the range of local shops and community groups. Those who continued to be actively involved in the community were usually assisted by a companion or supporter, and had access to private transport.

The main challenges of living in the Kiama area for people with dementia included lack of community understanding about dementia, limited access to appropriate activities and services, limited public or community transport options and worry about being susceptible to ‘small town gossip’.

The audit tool identified some areas for improvement such as the need for clearer signage, maintenance of footpaths and the need for more pedestrian crossings.

The interviews indicated people with dementia were involved in a range of activities both at home and in the community.

Commonly reported activities at home included:

- gardening
- watching television
- domestic tasks such as dusting and meal preparation.
Commonly reported activities in the community included:

- walking
- going to local cafés and restaurants
- shopping
- attending medical appointments
- participating in a range of social and volunteer groups.

Some people with dementia and their supporters modified their home environments and day-to-day tasks (for example taking a reminder list to the shops). Modifications were critical for facilitating continued involvement in activities and provided them with an important sense of independence, purpose, and identity. Another helpful strategy was to let particular business owners (e.g., bank managers, pharmacists) know about their dementia diagnosis so they could receive assistance if needed.

People with dementia enjoyed spending time with family and friends both at home and out in the community. They enjoyed visiting cafes and shops where they were ‘known’. They also valued mingling with acquaintances and other community members as this made them feel part of their local community. However, some people with dementia experienced difficulties socialising and being involved in the activities they previously enjoyed. Others experienced difficulties making new relationships, strained or distancing of some existing relationships, and difficulty getting to places on their own.

Nearly all community members (87%) agreed they would like to live in the Kiama area if they themselves had dementia. Reasons for this included:

- perception that health professionals would listen to them
- friendly and supportive atmosphere
- availability of dementia and aged services
- beautiful natural environment.

The challenges of living in the Kiama area identified by community members were similar to people with dementia and included:

- low awareness/understanding of dementia by community members
- difficulty finding information about dementia friendly services
- limited transport options
- difficulties accessing health specialists.

**What do local community members think about dementia?**

Surveys with 123 community members found that most (74%) knew someone with dementia and the vast majority (91%) were happy to spend time or have a conversation with a person with dementia. Despite this, only around half (51%) considered themselves to have a good understanding about the condition. Some people had low expectations of interactions with people with dementia, for example over 30% agreed that complex and interesting conversation could not be expected from most people with dementia.

What are the challenges for local organisations in providing services for people with dementia?

Surveys were conducted with 22 organisations that provided services to people living with dementia in the Kiama area. Whilst the vast majority of services and organisations surveyed (96%) had direct contact with people with dementia, most (62%) had difficulty finding information about local dementia services. Other challenges included:

- difficulty promoting their service/business
- funding issues
- transport difficulties.

There were also ‘dementia-related’ challenges such as:

- difficulty accessing appropriate clients
- limited community understanding of dementia
- resistance from some clients to receive support
- clients forgetting appointments.
Putting the research into practice

Two local groups have formed to implement a Kiama Dementia Action Plan. The first group is the Dementia Alliance and includes people with dementia and their supporters, and relevant stakeholders (e.g. members from Kiama council, transport services, and aged services) and is responsible for developing and carrying out the Action Plan for dementia friendly activities in Kiama.

The second group is the Dementia Advisory group which is made up exclusively of people with dementia and their supporters. They will oversee the activities of the Dementia Alliance, as well as develop their own activities.

What dementia friendly activities have been happening in Kiama?

As part of the research, the University of Wollongong consulted with ten local stakeholders (including services, clubs, community groups) and conducted nine information sessions for local groups (including services, clubs, carers groups) with over 160 attending in total. Additionally Alzheimer’s Australia held two public information sessions to increase community awareness and understanding about dementia and the Dementia Friendly Kiama project.

Several organisations have taken the first steps to become officially endorsed by Alzheimer’s Australia as ‘dementia friendly’ businesses. Over the coming months they will undertake activities such as environmental audits and staff training to become more dementia friendly.

Local newspapers and the Dementia Illawarra website have published several positive stories about people with dementia in the local area.

A website (dementialS.com) developed by the University of Wollongong with the Illawarra Forum and local Dementia Services Network was launched in November 2014. It provides a portal of information and local services (including social and support services) and events for people living with dementia and their supporters. This website will continue to grow and develop over the next two years.
Future Plans for Action

Priorities for the Kiama Dementia Action Plan are still being finalised by the Dementia Alliance but will likely include:

- local program of educational events to raise awareness and reduce stigma including tailored information for specific groups
- resourcing general practitioners to ensure newly diagnosed people are linked to local education, services and support networks
- a directory of community services specific for people living with dementia
- a dementia “expo” for people living with dementia and their supporters as well as businesses and service organisations
- actions to improve access to transport
- participation of people living with dementia in Kiama’s accessibility committee
- support for organisations to use the Alzheimer's Australia Dementia Friendly Business Tool-kit to increase community engagement of people living with dementia
- a ‘Dementia and Driving’ workshop
- dementia friendly walking groups
- a dementia friendly choir.

The Dementia Advisory Group is also planning a range of activities for people living with dementia including social outings.

Contacts

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For more information about other local dementia activities and services visit: www.dementialS.com