



Developing a Dementia- Friendly Christchurch

Perspectives of People with Dementia

Karen Smith

Canterbury
District Health Board
Te Poari Hauora o Waitaha



Overview

In 2011 a consortium of health and social care providers, people living with dementia and their support people met in Wellington as part of the National Dementia Cooperative to discuss a number of ways in which to improve the quality of life for everyone affected by dementia. One of the topics discussed was the need to embrace the growing global trend to develop dementia-friendly communities in New Zealand. This was in response to the Alzheimer's Disease International's (2012) findings on the growing incidence of dementia worldwide, which is likely to have enormous financial implications for health and social welfare providers both now and in the future.

A number of countries around the world have already begun to take action by addressing the need to develop strategies aimed at improving the quality of life for everyone affected by dementia, which not only includes anyone with a diagnosis of dementia but also anyone providing care or support for them. In many cases, this has resulted in strategic plans to develop dementia friendly communities, with some countries having already put some of those plans into action, notably the UK, France, the Netherlands, Canada and Australia.

The Ministry of Health for New Zealand is yet to determine a strategic plan to develop dementia-friendly communities nation-wide, therefore, this report has been devised to offer a starting point. Furthermore, Christchurch is currently in a unique position whereby it has the ability to capitalise on the devastating earthquakes of 2010/11 by incorporating the very latest principles of good dementia-friendly design, along with assistive technology, as part of the rebuild process.

The main objective of this report is to acknowledge, validate and disseminate the perspectives of people living with dementia as to what they considered might make Christchurch more supportive of people

with dementia to everyone involved in the rebuilding and redevelopment of Christchurch city. The individuals concerned included people living in their own homes as well as those living in care facilities.

Acknowledgements

I wish to thank first and foremost all of the participants in this study who invited the interviewers into their homes, giving both their time and hugely valuable contributions.

Special thanks go to Dr Matthew Croucher and Dr Susan Gee for their ever enthusiastic support for this project. Of course, this would never have been achieved without financial support therefore special thanks are extended to our sponsors – Canterbury District Health Board and Age Concern for supporting and funding our project. Sincere thanks go to Tal Sharrock – Graduate Student in Physiology and Public Health from the University of Otago – who assisted with participant interviews and has been instrumental in supporting me to collate our data; Lisa Phillips for her invaluable contribution to the transcribing process; Alzheimer’s Canterbury, Canterbury District Health Board’s Psychiatric Services for the Elderly, Bupa at Cashmere View, Homestead Ilam, Saint Allisia Lifecare, the Harakeke Club, and the Wigram Dementia Support Group for aiding our recruitment drive; Christchurch Library Services, Christchurch City Council Leisure Services; and all the Christchurch based medical centres, sports clubs, shops, cafes and services that contributed to our publicity campaign.

Front cover photograph courtesy of BUPA New Zealand

Contents

	Page
Introduction	6
What is a dementia-friendly community?	8
Making Christchurch Dementia-Friendly	15
Section 1: Dementia Awareness and Education	19
Section 2: Community Services	26
Section 3: Health Services	33
Section 4: Networks	43
Section 5: Buildings and Design	46
Section 6: Transport	53
Section 7: Access to Information	57
Section 8: Leisure	61
Section 9: Outdoor Environments	66
Section 10: Safety	71
Summary	76
References	79

Introduction

Dementia currently affects around 44 million people worldwide and approximately 50, 000 of those people live in New Zealand (Alzheimer's Disease International, 2014). These figures are expected to treble by 2050. The estimated cost to the nation in 2011 was said to be around \$954.8 million and this figure will inevitably rise alongside the growing numbers of people predicted to be affected by dementia (Alzheimer's New Zealand, 2011). Incidentally, the term "affected by" does not simply relate to those with a diagnosis of dementia. More rather it includes everyone caring for them, both paid and unpaid.

In spite of the numerous international research projects underway aimed at finding effective treatments and, ultimately, a cure for the various types of dementia the World Health Organisation (2012) recognises the need to find constructive ways to support people living with dementia right now. One solution is to consider our physical environment and to determine how far it aids the needs of a person living with dementia. Another solution is to look at how well the general population understands dementia in order to be more empathetic and supportive. By doing so, we are striving to make our communities dementia-friendly.

What is dementia?

Dementia is an umbrella term used to describe a number of progressive illnesses that affect a person's memory, reasoning, behaviour and ability to carry out every day activities, such as washing and dressing or preparing a meal. As it progresses dementia often affects a person's ability to communicate their needs in a widely acceptable manner as word-finding difficulties and the ability to comprehend the spoken word becomes more profound.

There are many different types of dementia but the four most common ones are Alzheimer's disease, vascular dementia, dementia with Lewy bodies and Fronto-temporal dementia. Rarer causes of dementia include Huntington's disease, Parkinson's disease, posterior cortical atrophy and supranuclear palsy. Korsakoff's syndrome is associated with heavy alcohol consumption and while still quite rare numbers are increasing in line with current trends in alcohol misuse both nationally and internationally.

Dementia does not correlate with part of the ageing process, however, the likelihood of developing dementia increases the older we get. Yet for some, especially those with one of the more rare types listed above, onset can occur before a person reaches the age of 65 years. Some providers of health care services report seeing a steady increase in the number of people under the age of 65 years with dementia but current research statistics do not reflect this upsurge (Young Dementia UK, 2014).

What this means in broader terms is that people with dementia are generally fitter and more active nowadays compared with, say, 20 years ago. Even where a person is over the age of 65 advances in medicine and greater access to health information has also contributed to a much fitter older population.

What is a ‘dementia-friendly’ community?

The concept of dementia friendly societies has emerged in countless different ways across the world but the common thread that brings these initiatives together is the desire to promote a better understanding of dementia and to reduce the social isolation and stigma that is so often experienced by the person with dementia.

Alzheimer’s Australia (2012, p.5)

While there is no universal definition of a ‘dementia-friendly community’, it is widely accepted that such a community is one that has a physical environment and a social community conducive to the needs of a person with dementia. For instance, it uses appropriate signage, given in both word and picture format, and is designed using the latest assistive technology; providers of local services, such as leisure and retail services, are educated about the effects of dementia in order to provide appropriate levels of support; people with dementia have access to local groups and are facilitated to develop and maintain social networks; and there are a range of support services, such as home based support, readily available (Milton, 2012; Mitchell, 2012; Lakey, 2012).

Alzheimer’s Australia’s *Dementia Friendly Societies: The Way Forward* report uses a definition of dementia-friendly proposed by Sam Davis and colleagues in 2009:

“A cohesive system of support that recognizes the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way.”

One of the features of this definition is that it prioritises the experiences of the person with dementia. As Milton (2011) argues, the voices of those with dementia and those who care for them should be “at the start and the heart of the process of creating dementia-friendly communities.” Thus the first step is to ask people with dementia and their caregivers what can be done on a community level to improve the quality of their daily lives, and then the next step is to create alliances that bring people and organizations together to implement these changes (Tingley, 2013).

Dementia-Friendly Initiatives

Many countries around the world are undertaking initiatives to create dementia-friendly communities aimed at removing the stigma often associated with dementia; reducing the risk of social isolation, which has been recognised as a contributing factor in the rate of progression (Alzheimer’s Society UK, 2013; Hughes, 2012; Hulko, 2009); raising awareness of the effects of dementia on those experiencing it and of those supporting a person with dementia amongst the wider population; and facilitating independence for people with dementia.

Global Initiatives

The very first national Alzheimer plan was developed in France in 2001 by Girard, which included the implementation of a network of memory consultants, the introduction of day centres, and measures to improve the quality of care for people with cognitive impairments living in residential care facilities. In 2007 Alzheimer’s disease was declared a major national concern (Alzheimer Grande Cause Nationale). Since then, France has been carrying out numerous research projects examining genetic links and searching for an effective treatment (Guisset-Martinez, 2012).

The Netherlands produced a four year National Dementia Programme between 2005 and 2008 in conjunction with the Ministry of Public Health, Welfare and Support and Alzheimer Nederland (Alzheimer Europe, 2014). This involved developing a network of regional care providers on a voluntary basis aimed at improving the quality of care for people with dementia and their families.

This led to the national standard for dementia care being established in 2011, which encompasses all professional guidelines, best practices and evidence based intentions.

In 2009 the UK government launched “Living Well with Dementia: A National Dementia Strategy”. This is a five year plan aimed at raising awareness of dementia; ensuring earlier diagnosis in order to offer more timely treatment options; and develop a range of services that meet the changing needs of the person with dementia and their family/support people.

In December 2013 the UK also staged the International G8 Dementia Summit in London bringing world leaders and global experts together to implement strategies to tackle the global issue of dementia, which includes plans to increase funding into human research with the ambitious aim of producing an effective treatment or cure for Alzheimer’s disease by 2025 (G8 UK). This will be led by academia and industry partnerships in Canada and France.

Localised Projects

In 2010 the Hogewey dementia village was developed on the outskirts of Amsterdam in the Netherlands (Henley, 2012), which was designed to accommodate the needs and lifestyle choices of individual residents. It

comprises of 23 different care homes with up to seven residents and two care staff in each one, all situated within a secure village-like environment. Each care home has a unique design, aimed at meeting each resident's particular taste. There is ample open space with walkways and boulevards, a cafe, movie theatre, restaurant, minimarket and hairdressing salon.

While Hogewey presents as an ideal model as far as the future of dementia care facilities is concerned, it could be argued that by developing stand alone, gated villages we are, in fact, in danger of further marginalising and stigmatising people with dementia. Such a model potentially removes people living with dementia from the wider community and limits opportunities for the wider community to interact with people living with dementia, especially those with severe dementia. However, it is commendable that Hogewey was developed after consultation with people with dementia and their support people, with safety being a key element.

Life Care in South Australia have coupled up with the Do-It-Yourself retail chain, Bunnings Warehouse, to enable people living with young onset dementia to participate in a range of work activities, with the support of a "buddy" – a volunteer who has received training on how to support a person with dementia (Alzheimer's Australia, 2012).

An evaluation of this programme revealed that people living with dementia had improved self-esteem, increased mental alertness and were more interested in life in general. Furthermore, the programme has helped to raise awareness of dementia amongst staff and the wider community.

South Korea has begun training thousands of people, including children, to become “dementia supporters” in order to recognize symptoms and care for people with dementia (Lee, 2010).

The UK has also recently completed a pilot study aimed at educating school children about dementia (Saad, 2012), as well as leading the way in terms of dementia design.

New Zealand has made some headway in terms of dementia education for paid caregivers through the ‘Walking in Another’s Shoes’ programme (Gee, Scott and Croucher, 2013), which was established in 2008 in Christchurch as a means to improve communication between paid caregivers and people with dementia, both in care homes and in people’s own homes, and is currently expanding throughout the whole of New Zealand.

While there is a heart-warming array of individuals, groups and businesses around the world creating dementia-friendly initiatives, there is also a role for leadership, coordination, and strategic planning at a national and local. This includes national charters where organisations and businesses can become signatories.

In the UK examples include the Dementia Action Alliance whereby organisations and businesses sign up to adhere to the principles of a dementia-friendly community. This can be achieved by ensuring staff receive appropriate education and training in order to offer a more supportive service to people living with dementia (Innovations in Dementia, 2011) – Included in this is the Hampshire Dementia-Friendly Toolkit, which, in addition, has a checklist that ensures communities also work towards adopting the principles of good dementia-friendly design, e.g. appropriate signage, lighting, seating, flooring and navigation; the dementia friendly financial services charter (Alzheimer’s Society UK,

2013b), and the dementia friendly communities recognition process (Alzheimer's Society UK, 2013c).

Recognised dementia friendly organisations can display the relevant symbol, such as a forget-me-not in the UK, a purple angel in the US, or a handkerchief with knots in Bruges. It also includes initiatives with local government leadership such as those of Stirling in Scotland which has adopted the “Stirling the real dementia friendly city” as a corporate vision for 2013-2016 (Stirling Council, 2013), or Bruges in Belgium which has a 5 year action plan called “Together for a dementia friendly Bruges” (cited in Alzheimer's Australia, 2013).

By adopting dementia-friendly initiatives communities become more inclusive of everybody, not just people living with dementia. Innovative developments in design and building, technology and assistive technology, and widespread education and good customer service all serve to support people with other physical and mental health problems, young families and international visitors for whom English is a second language.

As far as rebuilding Christchurch is concerned a dementia-friendly model has enormous potential for the future development of the city and both its present and future population. Not only will it meet the needs of everyone living in and visiting Christchurch but it has the potential to be the very first world-leading example of a truly dementia-friendly city.

Making Christchurch Dementia-Friendly



Between 2010 and 2011 the city of Christchurch suffered three major earthquakes resulting in extensive damage and the need for a complete rebuild of the Central Business District (CBD) and local community centres.

After the devastating earthquakes Christchurch is in a unique position to engage with designing for dementia-friendly communities as part of its rebuild process. As the recovery Strategy points out

“Recovery is inherently future focused and there will be opportunities to “build back better” when repairing damage done by the earthquakes.”

The need to rebuild can indeed be seen as opening opportunities to be amongst the first specifically designed, appropriately serviced and empowering dementia friendly communities in the world. An essential first step in this process was to gather the views of Christchurch people living with dementia.

A team of researchers from Canterbury District Health Board led by Karen Smith have undertaken a qualitative study to seek the perspectives of people with dementia. The aim of the project was to gather insights from Christchurch people living with dementia about what would make it possible for them to live better in their community, and to distil this local advice to those who can make a difference in a series of user-friendly 'tool-kits', such as the one developed by Hampshire County Council in the UK.

26 participants between the ages of 60 and 95 years of age, and with a diagnosis of dementia, which was variable in terms of stage of progression, took part in an individual face-to-face interview. Each interview was between 20 minutes and 2 hours and 30 minutes in duration and took place in each participant's own home (including those living within a residential care facility). Some participants chose to have a support person present during the interview. All interviews were audio-recorded and transcribed.

The methods of interviewing used for this project were Life History Narrative and Appreciative Inquiry. Each participant was asked to talk briefly about themselves. Who they were? What did they value? Followed by a number of open-ended questions, which included:

"What is good about your life?"

"What things do you like to do?"

"What would be the perfect day for you? What would you do?"

"When you go out in Christchurch what sort of things do you do? Where do you go?"

"Is there anything that you wish was different to help you?"

"Can you tell me about a time when you went out to do something and it went really well? What do you think helped it go so well?"

“Are there things that you used to go out and do but have stopped doing them? Why did you stop doing [that]? What might help you start doing [that] again?”

“Are there new things you would like to be able to do? What do you feel is stopping you? What might help you to start doing them?”

“So, thinking about where you live and the places you go – what is good about your community? If you could make a wish for your community what would it be? Is there anything else?”

“Is there anything that you would have liked to have been asked about in this interview that you feel we have missed out?”

From these interviews we uncovered the following main themes that people living with dementia in Christchurch have identified as being of significant importance as a means of ensuring the city works towards becoming more dementia-friendly:

- Dementia awareness and education
- Community services
- Health services
- Networks
- Buildings and design
- Transport
- Access to information
- Leisure
- Outdoor environments
- Safety

Our findings reveal that there are people living with dementia in Christchurch who want to try their hand at new, outdoor leisure pursuits while others, especially those living in care facilities want to maintain their life-long domestic skills but are denied an opportunity to do so as a result of health and safety policies and guidelines.

New Zealand has many migrants, many of whom have chosen to live in this country because of its vast outdoor space and for an opportunity to engage in outdoor leisure activities. Therefore, it would appear appropriate for dementia care providers and other service providers to bear this in mind when considering how far their service meets the wants and needs of people living with dementia.

This is a unique opportunity for Christchurch but one that can be lost – as decisions are being made and plans are being drawn will they be embracing the best of dementia friendly and disability friendly design or could they be unintentionally creating barriers that will remain with us for decades to come?

In a Christchurch which is anything but dementia-friendly post-earthquake there is a chance to make a positive difference. This project is one step in learning from people living with dementia in order to turn these needs into action to create a dementia-friendly Christchurch.

Section 1: Dementia Awareness and Education



Universal dementia research that has previously sought the perspectives of people with dementia has concluded the need for dementia to become “normalised” (Innovations in Dementia; The Alzheimer Society of Ireland, 2012).

People living with dementia often speak of feeling embarrassed and stigmatised when out in their community, thus, resulting in lowered self-esteem; a reduction in confidence and loss of dignity (Cantley and Bowes, 2004). Yet, we argue that it is not dementia or its symptoms that negate such feelings but more rather the attitudes and level of understanding about dementia amongst the general public.

Such negative attitudes are not meant with malicious intent and often stem from misunderstandings that lead to widespread media use of derogatory labels, terminology and images. All too often media depicts people living with dementia as helpless, dependent and incapable of making decisions or choices (Penn and Wykes, 2003; McColgan, 2004). It can also focus its attention on activities that a person might not be able to do as opposed to those that they might, and use words such as “burden”, “demented” and “debilitating” to describe their experience.

The challenge, therefore, lies in reducing stigma and marginalisation, and promoting social inclusion and normalisation, by raising awareness about dementia and providing education and support to those in front-line services, including health and social care, community, transport and leisure services, and raising awareness amongst the general public.

Dementia training programmes already exist for paid care workers employed in hospitals and care facilities, such as the ACE dementia programme, and “Walking in Another’s Shoes” – an intensive programme offered free to care workers, activities coordinators and nurses working in dementia rest homes and dementia hospital level care facilities, developed in Christchurch and currently expanding throughout the whole of New Zealand (Gee, Scott and Croucher, 2008). However, our findings tell us that there is still a great need for further developments in the formal education of health and social care providers.

Case Study

Participant A has vascular dementia. After suffering a stroke he was admitted to hospital where his needs were met and staff had a good level of understanding about dementia. However, upon being transferred for rehabilitation, he would often find himself left for lengthy periods to figure out what he was supposed to be doing as regards his exercises. He would quickly forget instructions. Staff assumed that as he was now on a rehabilitation ward he was able to meet his own needs.

The above case study identifies how a person with dementia may present as being able to fully comprehend and retain information whenever it is first presented, yet health care workers need to regularly seek clarification from patients as to their level of understanding. Equally, additional support staff, such as, cleaning services and volunteers should also be made more aware of the needs of people with dementia, especially in relation to a person’s ability to give themselves food and fluids or regulate their own body temperature.

A number of high profile cases within hospitals in the UK have highlighted incidents of neglect where patients with dementia have

received insufficient food and fluids (BBC News UK, 2012). Cups and plates are often removed from a patient's bedside without them having being supported to consume food and fluids, with some staff wrongly assuming that it was the patient's decision to decline them. Furthermore, nursing staff are then unable to properly monitor food and fluid intake as a result.

Another participant in our study spoke about an experience he had with his General Practitioner (GP). Aware of his own short-term memory problems he asked his wife to accompany him to an appointment as he felt certain he would not be able to remember the details of the consultation or, indeed, give appropriate responses to the GP's questions. He describes his experience as follows:

"...one day we were in there and, anyway, he was asking me something there and my wife said, sort of answered him, and he said, "I am not talking to you, I am talking to him and I would like him to answer." ...it was real sharp and abrupt..."

(Person with dementia)

It could be argued that in this instance the GP was trying to ensure that the person with dementia was being encouraged to think and speak for himself. However, while this is to be encouraged it is also worth bearing in mind the preferences of each individual before and during consultations. There may be instances when a person with dementia may choose not to have the presence or input from their support person and there may be other times when their input is highly valued.

Good practice might involve a health or social care professional meeting with the person with dementia separately first and foremost, then separately with the support person, and then with both parties together. However, time may be limited for some health and social care workers,

in particular GPs. In this instance the support of a practice nurse could prove beneficial. They could be seeking collateral information from the support person while the GP consults with the person with dementia.

On the whole most participants spoke positively about health and social care providers. Even where dementia awareness, good communication between the person with dementia and/or support people, and practical assistance was erroneous it was widely recognised that staff intentions were usually well-meaning.

Of course, it is not only staff working in hospitals, rest homes and other social care environments who interact with people living with dementia as part of their everyday lives. For many, their journey starts and generally spans a number of years while continuing to live in the community. Therefore, dementia education and awareness needs to be extended to service providers, industry, schools, in fact, everyone.

The UK recently pioneered the dementia awareness in schools initiative as part of its “Intergenerational Schools Project” (Alzheimer’s Society UK, 2013). This involved introducing children to people with dementia in order to gain insight and understanding of dementia as well as develop empathy skills, learn more about older people and illness.

Other dementia awareness and training initiatives in the UK have involved banks, supermarket chains and churches (see section 2).

EDUCATE (Early Dementia Users Cooperative Aiming To Educate) (Local Government Association UK, 2014) is a peer support group that was set up as part of the UK Government’s “Ageing Well” programme to inform others about the experiences of people with dementia.

The Ageing Well Programme also identified a number of recommendations for front-line service providers aimed at supporting them to recognise signs and symptoms, consider how their attitudes, set-ups and signage can be more helpful to those experiencing confusion, together with reviewing the built environment and making any useful changes where possible.

The experiences of younger people with dementia (those aged under 65 years) can present with many challenges, more often in the early stages of the disease.

Dementia is widely perceived as a disease that affects older people only. While young-onset dementia as it is known is comparatively uncommon there is a growing increase in the number of people affected by it. Some contributory factors include a family history of young onset dementia, stroke (may lead to vascular dementia), and the effects of long-term alcohol and/or substance misuse.

The needs of a person with young-onset dementia are frequently unidentified or fail to be acknowledged as symptoms are often mistaken for clumsiness, absent-mindedness or, at worst, an overall belief that the person is incapable. In some cases this has led to a person's employment being terminated.

Case Study

Participant B has young onset Alzheimer's disease. His symptoms began whilst in full-time employment. He became very forgetful and routinely began to misplace items in his workplace. His colleagues found this highly amusing and would exacerbate the problem by deliberately hiding other items from him as a joke. This caused Participant B considerable stress, making it difficult for him to continue carrying out his role.

In the case of this participant he endured many months of mockery and intimidation before anyone began to question what might be occurring for him. Once he received a diagnosis of dementia his manager and colleagues became more supportive until such time that he was no longer able to continue working.

Had the employer had a basic understanding of the signs and symptoms of dementia, Participant B might have received a more timely diagnosis. The employer may have been in a position to offer an appropriate level of support, enabling Participant B to continue carrying out his role. Alternatively, a more suitable role might also have been possible.

It is worth noting that some signs and symptoms associated with dementia, such as confusion, short-term memory problems, or changes in behaviour can also be the result of other health problems, including infections, vitamin deficiency, depression, among others. Therefore, it is important for employers, colleagues, friends and family to note any behavioural changes and encourage the person to seek medical support. In light of a person's potential fears, it might be worth emphasising the need to rule out all possible causes.

Key Points

- Loss of confidence for a person with dementia is often determined by the attitudes and level of understanding from the wider community.
- Negative attitudes towards people with dementia are not derived from malicious intent – more rather they are depicted from inaccurate media perceptions.
- Younger/people of working age with dementia report a lack of awareness and understanding on the part of employers.

- Dementia education and training initiatives have been shown to significantly improve the lived experience for people with dementia.

Section 2: Community Services

There are many global initiatives being developed to ensure community services, including business and leisure facilities, provide a service that acknowledges and supports the needs of people living with dementia. This includes making sure staff are sufficiently trained to recognise when a person might need additional support and how to communicate effectively.



A number of UK banks are providing staff training in dementia, with some utilising mystery shoppers to ensure the banking experience for a person with dementia is a positive one. Many of the UK's large supermarket chains are also developing guidance on how the retail sector can work towards becoming more dementia-friendly.

A local college in Crawley, south-east England is offering hair and beauty treatments specifically for people with dementia in an attempt to raise awareness in their trainees before they embark on their career.

Good dementia-friendly design, along with other environmental factors, is equally important. We shall refer to these more specifically in section 5.

The majority of participants spoke favourably about their local community services, citing good, friendly, supportive service in shops and stores, cafes and restaurants, and taxi services, especially those

that provided a free telephone service within the supermarket or mall. Here is what one participant had to say about this:

“You come out of the double doors, which are onto the Main South Road, and just on the wall on the right, there’s the phone and you just pick it up...If you were visually impaired or very frail the phones are just out there and you just pick it straight up and the operator answers. You don’t have to dial anything.”

(Person with dementia)

This participant went onto tell us how the taxi drivers working for this particular company would also carry their shopping from the car to their front door and would always allow them plenty of time.

Library services were viewed to be among the most favourable of all community services. Since the earthquakes of 2010 and 2011 some library services have responded to the needs of their local community by providing a mobile service. This was highly valued by those participants receiving them.

Another participant responded by telling us they liked the way everything was set out in their local library as it made it easier for them to find exactly what they were looking for.

Librarians who responded to telephone requests were deemed very supportive. One participant told us of their experience:

“Everything is done [for you]. You walk in and if you have been there [before] you say “Hello. Here we are.””

Other participants referred to the accessibility of the internet and free Wi-Fi being very useful, especially where they were bound by financial constraints preventing them from owning a home computer.

Faith and religious services were valued by a number of our participants, especially for one living in a rest home. However, while there is an opportunity for them to attend a weekly religious service within the rest home this is not focussed on their particular religion. Family have previously supported this participant to attend the church that they were associated with before they developed dementia but the noise level and congregation numbers proved too overwhelming as their dementia progressed.

Once again, the UK is leading the way in terms of dementia-friendly initiatives as some religious groups are also striving to become more aware and more inclusive of those members of their congregation who have dementia. Over 20 churches across the West Midlands have expressed an interest in becoming part of a pilot aimed at influencing the way churches can raise awareness, improve their environment, and tailor church services to be more person-centred. The Anglican Diocese of Lichfield now forms part of the Dementia Action Alliance.

Most participants provided positive accounts of their experiences in cafes and restaurants. Service was generally perceived as friendly and accommodating. A number of participants commented on how they particularly liked to visit places where finger foods were widely available, especially where they had visual or physical disabilities, including tremor. In such instances, participants were grateful where food and drinks were brought to their table, even where self-service was the norm.

Some participants reported having stopped dining out as they felt embarrassed by their disability. Yet, there was some consensus of opinion in that it was not café or restaurant staff who led them to feel embarrassed, more rather the attitudes and perceptions of other diners.

This was a more common experience for younger people living with dementia.

As far as shopping facilities were concerned almost all of our participants preferred to shop at smaller centres or malls. Most of them described the larger inner-city malls as “overwhelming”, “noisy” and “too busy.” One participant spoke of their fear when they were unable to locate their partner amongst the crowds.

Comments around service personnel were variable. One account was from a person who observed another person deemed to have a cognitive disability while out shopping:

“There was a dear old man and they packed everything up...Then she [the assistant] helped him with his card, but he did the thing [entered his PIN number]. She helped him with that and she checked that he had put it in his wallet before he left...So caring, and she didn’t mind about the other people waiting...”

(Person with dementia)

Other accounts were far less positive. One participant disliked how shop assistants would often talk to their support person rather than them, even when it was they who would be making the purchase.

Case Study

Participant C is a person with Alzheimer's disease coupled with visual impairment. He tries to remain as independent as possible but can become frustrated and irritable whenever he feels overwhelmed by his own difficulties and the environment around him. While trying to purchase a Lotto ticket from a kiosk in a busy shopping mall he asked for assistance but was denied. When he tried to explain about his visual problems staff were still reluctant to help. This resulted in an angry exchange of words, with the gentleman being told he was "rude".

Experiences like the one featured above are not uncommon for a person with dementia. All too often their needs go unrecognised. Once they become frustrated and angry, which may manifest itself in a hostile exchange of words or by throwing things, for example, they are labelled, "aggressive", "difficult" or "challenging". There have even been reports of people with dementia being arrested and charged with inappropriate behaviour. In addition, one participant spoke of how they felt there was a lack of understanding and awareness of dementia among emergency service personnel. This was particularly so as far as the police and emergency call centre staff is concerned.

Meanwhile, another participant told of how their local police officer devoted his own time to helping them remove their outdoor plants prior to the repair of their earthquake damaged home.

The UK Government Association Report entitled "Developing Dementia-Friendly Communities: Learning and Guidance for Local Authorities (2014) summarises some general training recommendations for service providers to enable them to be more supportive of people with dementia living in their communities:

Basic awareness training – what this might include:

- Information about dementia – signs and symptoms, progression of the illness
- The impact on everyday life – things people might struggle to do
- Recognising when things change for customers they see regularly.
- Understanding the emotional support needs of people with dementia and their carers.
- How to communicate.
- Knowing when to ask for help from a colleague.
- What help is available for people with dementia and how to refer them.
- Bespoke topics for particular staff groups, for example helping people using transport to make sure they're going in the right direction and have confidence that the bus will drop them where they need to be.

The Government Association (UK), (2014)

It is important to bear in mind that for many people with dementia their ability to maintain a sense of control can be significantly compromised. This is largely due to atrophy, or shrinkage, in an area of the brain known as the “frontal lobe”, which is responsible for controlling our

inhibitions. In most cases, a person with dementia may not have presented as angry or volatile prior to developing the disease.

Like many other physical and/or mental health problems, being able to recognise when a person with dementia needs support and acknowledging their frustrations is one of the very first steps in ensuring good dementia-friendly service. A welcoming smile can also be hugely beneficial. Additional approaches include facing the person while communicating and using simple, clear words that the person can recognise and understand. For those whose dementia is more advanced the use of fewer words, or even pictures and symbols can be incredibly useful. Allowing a person enough time to process what is being communicated is paramount.

Section 3: Health and Social Care Services



Research indicates that hospital admission is highly likely to exacerbate the symptoms of dementia (HammondCare, 2011). For a person with dementia, the hospital experience can be a stressful and frightening one. The same can be said for staff caring for a

person with dementia, especially where they fail to understand the needs of the person with dementia due to lack of awareness, which may result in expressed emotions of anger and frustration from both parties.

A number of studies have also identified inadequacies in community services for people with dementia (Cobban, 2004; Innes and Sherlock, 2004), especially in rural communities.

Where available an overwhelming majority of participants in our study cited non-government organisations and voluntary organisations as providing the best dementia-friendly services. Day services for people with dementia and/or Parkinson's disease, and/or visual impairment were very well received.

What participants liked about these services was the ability to feel comfortable and not have to worry about how they presented as they were among other people just like them.

"...all the meetings we had down there...about once a month on Friday afternoon, Friday morning, and that was very enjoyable. You learnt a lot

from the other people in the room who had your problems or had similar problems and we were able to talk things over.”

(Person with dementia talking about their local support group)

“You can get away [from family and friends] and then if you put your foot in it or...you know...if you start telling a story and lose track in the middle...and they look at you as if you’re silly, but if you are with people that have got the same problems...”

(Person with dementia talking about their local support group)

The friendship offered by non-government support groups was highly valued by a number of the participants, coupled with the “helping spirit”.

Artzheimer’s – an art appreciation group developed especially for people with dementia – received high acclaim. One participant described it as

“...probably the most important thing that is happening for me...you’re meeting other people with the same difficulties as you but with the same appreciation of art...”

(Person with dementia who attends the Artzheimer’s Group)

Community nursing services were viewed favourably along with emergency medical services, including ambulance crew, after hours emergency centres and the Christchurch City Hospital emergency department.

Case Study

Participant D has dementia, coupled with mobility problems, which impact on his ability to attend to his own personal care needs. His wife is unable to provide the level of support he requires.

He receives assistance with bathing via the community nursing service. They understand and address his physical, cognitive, social and psychological needs by establishing a good rapport, finding out from him and his wife about his likes and dislikes, and good use of humour.

The ability to establish good working partnerships with the person living with dementia and their support people is essential when striving to offer an effective dementia-friendly health or social care service. It is important to embrace the concept of “personhood” (Kitwood 1997) – what makes this person who they are? What are their values? What are their achievements? How would they like to be recognised?

Every individual is unique therefore a “one size fits all” approach to dementia care is inappropriate. For example, one person may insist on being addressed as “Mr” or “Mrs”, expect to use good manners, and prefer a health worker to adopt a pleasant but professional approach at all times. Meanwhile, another person may only accept support where an informal approach is taken, with use of friendly banter and good humour.

Finding out about a person’s life history is another crucial factor to take into consideration when supporting a person living with dementia. Seemingly unusual, odd or even potentially harmful behaviour can sometimes correlate to past occupations or life experiences. For instance, a woman with an occupational history of being a care worker in

a rest home, who now has dementia and is residing in a rest home herself, is seen force-feeding another resident with dementia. Her actions might be deemed problematic and a risk to others, sparking concern from staff and management. While this may well be the case we need to think about what it was that this woman was trying to achieve. Indeed, she could have been living in a part of her past that informed her she was there to help others with their meals. However, the insight required to assess the risks associated with this intervention, e.g. choking, may be lacking.

Rather than detract from the woman's role identity it may be helpful to provide tasks that are in-keeping with her role and maintain a sense of personhood, for instance, by asking her to prepare the tables at meal times or wipe the condiments afterwards.

One participant residing in a care facility told us:

"I have to be very careful...well, once or twice I pushed a resident back to her room, but they (staff) weren't so keen on that because they are supposed to do the handling..."

(Person with dementia living in a care facility)

All too often people living with dementia are assessed and even judged on the things that they are no longer able to achieve rather than those that they are. Health and social care workers need to devise care plans and coordinate activities based on the development of a person's strengths rather than weaknesses.

Policies and procedures, especially in care facilities, usually take precedence over the preferences, wants, needs and personal values of a person with dementia. Much conflict of interest arises from policies focussed on infection control, particularly as far as handling food and

laundry is concerned. Yet, how a person presents themselves is a significant part of their identity and large scale laundries in care facilities are seldom conducive to the individual preferences of residents.

Case Study

Participant E is a lady with dementia who resides in a dementia rest home. She has a life-long love of fashion and has a wardrobe full of designer clothes. She is not permitted to hand-wash her clothes in the communal laundry, nor is there an accessible sink whereby she could wash them. Her clothes have previously been returned to her in an irreparable state and so her daughter now takes them home to hand wash.

A balance between meeting the needs and supporting the strengths of a person with dementia and adhering to current health policies can be achieved with a little creative thinking and planning. Some care facilities provide small laundry areas or kitchenettes whereby life-long domestic skills can be maintained by the person living with dementia while minimising the risk of cross-contamination. Other useful features in care facilities may include washing lines in communal outdoor areas where residents can be supported to care for their clothes as they see fit. There are good examples of this currently in facilities within Christchurch and the surrounding areas.

One participant who was residing in a dementia rest home spoke of her boredom, citing the lack of meaningful activities as a major factor. When asked what might make life better for her? She replied,

“More to do. More...things, but then again a lot of people (other residents) can’t do the things. What I have to do is accept..is, do I want to say here? And, you know, do the things like Housie. I find that a bit...boring.”

(Person with dementia living in a care facility)

Participants who resided in care facilities largely enjoyed “Happy Hour” – an opportunity to listen to music, either live or recorded, while enjoying a glass of their favourite drink.

An opportunity to get out and about in the community was also regarded with high importance by people living in care facilities yet most participants told us that opportunities were limited.

Some participants in our study spoke of how health and social care workers will often ignore them and respond as though they are not present when in the company of a support person. This is in contrast with the participant in section 1, who told us of his dismay when being accompanied to a GP appointment by his wife, only for her to be told that her input was not required.

Of those participants who shared their experiences of in-patient hospital services most accounts indicated a need for greater dementia awareness.

Case Study

Participant F is a gentleman with advanced dementia. He can become increasingly confused and disoriented once away from his familiar environment. He was admitted to hospital with chronic chest pain. He received excellent care while in the emergency department but problems arose once he was transferred to an in-patient ward. While being advised of his diagnosis and corresponding difficulties, staff failed to acknowledge and account for these. This resulted in this gentleman leaving the ward, eventually being found in the operating theatre. There was a lack of staff in the theatre at this time. This experience resulted in tremendous anxiety for both this gentleman and his wife who thought that his safety would be guaranteed while in hospital care.

Situations such as the one featured above are not uncommon in large public hospitals. Wards and departments are usually unlocked and staff are busy attending to patients' needs, often behind a closed curtain or in a private room.

The patient experience for a person with dementia can be an overwhelming and frightening one, especially where the ward contains lots of medical equipment, which can also be noisy and disruptive. The person with dementia may be desperate to find a place of comfort and/or familiarity, occasionally becoming lost in the process.

However, there are some simple measures that can reduce the risk of events such as the one featured here from occurring.

If staff are aware that a patient has dementia ensure their bed is located as close to the nurses' station as possible. This will enable staff to monitor the needs and whereabouts of the patient more closely while also providing some reassurance to the patient that they are not alone.

A person with dementia may not recognise or know how to use the call bell system and may not be able to communicate when needing to access toilet facilities, therefore, ensuring there are toilet facilities nearby will also be helpful. People with dementia are more likely to recognise pictorial signs rather than written signage so having signage that consists of both is recommended.

Where a watch (staff who remain with the patient at all times) is required encourage them to interact with the person with dementia as they may find the close proximity of the watch intimidating or threatening.

Reminding the person with dementia of your name and designation each time you communicate with them may help to remind them of where they are and that you are there to support them. This approach can prove particularly useful where the person may be expressing some disinhibition (e.g. sexual) or where they may mistake you for a familiar person.

Remember, most behaviours exhibited by a person with dementia are triggered by fear. Their world may have become foggy and confusing, leading to feelings of anger and/or frustration. Pain and discomfort can also impact on the expressed emotions of a person with dementia. Assessing for pain and offering supportive interventions, as well as validating their feelings can dispel or reduce the potential for angry outbursts or emotional distress.

Assistance with personal care is one of the greatest areas of concern for people with dementia, support people and health and social care staff alike as the person with dementia is often unaware of their need for support. This can sometimes lead to episodes of angry behaviour, which many staff find difficult to manage. One participant in our study told of how he felt he had been treated like an elephant as he was pushed into the shower while in hospital.

Treat the person with dementia with dignity and respect. Many of us feel uncomfortable undressing, toileting, bathing/showering in the presence of others so bear this in mind when assisting someone to meet these needs. For instance, where safety when using the toilet is a concern give the person as much privacy as possible, such as wait outside of the toilet cubicle if possible or place a blanket or towel over the person's knees while they use a commode; wash and dress upper body parts before exposing lower body parts to avoid leaving the person feeling completely exposed and vulnerable.

Where a situation has proven challenging for health and social care staff managers or team leaders should be encouraged to offer staff an opportunity to reflect on the outcome by asking such questions as, "What worked well?" "How could we do things differently?" "What additional support might be useful?"

It is not always easy for a health or social care worker to think rationally in times of crisis or where a potentially harmful or threatening situation arises. Opportunities for self-reflection lessen the likelihood of creating a "blame-culture" and offer a chance to develop and learn from experiences, which in turn, works towards a more positive experience for the person with dementia and their support people.

Key Points

- Get to know the **Person** with dementia.
- Determine their likes and dislikes.
- Find out what level of support they want/need from family/whanau/friends?
- When caring for a person with dementia in a hospital or care facility identify possible causes for changes in behaviour, such as pain and /or other physical symptoms that may be resulting in additional distress.
- Provide opportunities for meaningful activity.
- Provide a safe, secure, reassuring environment while in hospital care.
- Develop good, effective, reflective team working relationships.

Section 4: Networks



Socialisation and the ability to form and maintain supportive networks have been recognised as contributing to the delay of progression in some dementias such as Alzheimer's disease (Bennet, Schneider, Tang, Arnold and Wilson, 2006; Fratiglioni, Paillard-Borg, Winblad, 2004).

The devastating earthquakes of 2010 and 2011 have had a significant impact on many communities in and around Christchurch, with the eastern suburbs enduring the greatest impact. This has resulted in large numbers of people being forced to leave their homes and move to other areas, while others remain in sparsely populated streets where there was once a thriving community.

Some of our participants told us of how various service providers were doing their utmost to maintain and strengthen their community, for

instance, by introducing a mobile library service where their library building is no more, and exercise classes being held in community centres or schools aimed at improving the physical, social and psychological well-being of the older population.

One of the messages being disseminated across the globe in an attempt to minimise the risk of developing dementia is to develop good social networks (Alzheimer's Disease International, 2012). In the wake of the Christchurch earthquakes this message has never been more applicable and has been extended to highlight the importance of getting to know your neighbours. Yet for some people in and around Christchurch this is currently proving more challenging.

As one participant living in one of Christchurch's eastern suburbs told us:

"When I go down shopping, there's hardly a soul I know now. I might bump into the odd person, you know, that I have known to say "Hello" to, that I have seen before."

(Person with dementia)

Another participant told us:

"The east side has changed. The people have gone...lots of people have gone. It's completely changed, but I still...I still maintain one contact, but I don't go over [to the eastern suburbs] like I used to. I...well, I spent hours and hours doing voluntary work in New Brighton and now I only get over once or twice a week."

(Person with dementia)

One participant's experience of their community was much more positive:

"...we have got some lovely neighbours and, you know, we've made a bit of an effort to get to know our local neighbours, which I think is important...I would encourage anybody with Alzheimer's [disease] to make sure they know their neighbours...you shouldn't have to have Alzheimer's [disease] to get to know your neighbours...we should all learn to be neighbourly and care about each other."

(Person with dementia)

Close communities were regarded as safe for people with dementia, with overall safety being highlighted by a number of participants as paramount.

Voluntary support services were well received from most of our participants, especially the monthly dementia support group held at the Wigram Air Force museum. This provides people with dementia and their support people with an opportunity to socialise, share experiences and offer peer support over a cup of coffee.

Some participants received support from a volunteer befriender, which again, was well received and highly valued, especially for those individuals who did not enjoy large group activities or social gatherings, or maybe even had little confidence, but who liked to get out into their local community.

Being able to provide support to others was recognised by two of our participants as a valuable networking resource. This coincides with recent findings in the UK Alzheimer's Society report, "Building Dementia-Friendly Communities: A Priority for Everyone" (2013) in which people with dementia also spoke of wanting to offer peer support.

Case Study

Participant G was asked by her local minister if she would like to volunteer as a hospital visitor within the retirement village where she resides. She has found this role to be of enormous benefit to both herself and the person she visits as it gives her a sense of purpose while improving the well-being of the other resident at the same time.

Networks not only provide people with dementia access to peer support but, in addition, can promote meaningful activity and role identity. As previously stated, people with dementia frequently report feelings of helplessness when, in fact, it is often the attitudes and/or lack of understanding about dementia that forces members of the wider community to focus on a person's inabilities rather than build on their strengths. Yet, it is people living with dementia who understand their illness far better than anybody else.

With more and more older people connecting to the internet online support networks are becoming increasingly more popular for people with dementia and their support people, especially since family and life-long friends become more geographically dispersed.

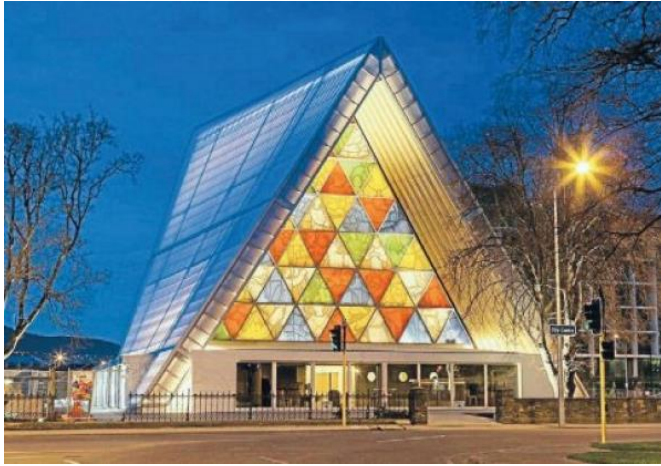
Some of our participants spoke of how they interacted on social networking sites, such as “Facebook” and “Grown-Ups”, which help them to feel useful and included amongst the wider society.

People with dementia and their support people are inclined to experience withdrawal from friends and family who struggle to comprehend dementia and, therefore, find it easier to disengage. This can lead to isolation for both parties, especially at a time when support and socialisation could not be more necessary.

Key Points

- People with dementia value the support of peers.
- People with dementia also like to feel useful and be given opportunities to offer their support to others.
- More and more people with dementia are resorting to using the internet to access information and seek support from specialist and voluntary agencies.

Section 5: Buildings and Design



Adequate, appropriate, user-friendly design is essential when addressing the needs of a person with dementia. Furthermore, such design principles not only have the potential to meet the needs of people with dementia but just about every member of society, from babies and young

children, to people with physical and sensory disabilities, people with mental health problems, and international visitors for whom English is not their first language.

Dementia-friendly design is one that is not over-complicated, quirky or overwhelming. It uses colours, contrast and features that clearly define spaces and objects, making them instantly recognisable and easy to navigate. It places a strong emphasis on internationally recognisable, pictorial signage, and lighting that minimises glare and shadowing.

People with dementia are frequently deterred from accessing busy public spaces due to feeling overwhelmed by multiple technologies, crowded places where tempo and noise levels are high, and changing landmarks, something that has proven unavoidable in Christchurch post-earthquakes (Brorsson, Ohman, Lundberg and Nygard, 2011).

Multiple public buildings throughout the world, including airport terminals, shopping malls and apartment blocks, feature shiny, polished floors that not only pose a safety risk when they should become wet and slippery but, for a person with dementia, or who may have problems with perception, can appear to look like water. This can incite feelings of fear

and uncertainty in some individuals, even preventing them from entering public spaces.

“When you go in there [the shopping mall]...you don’t know whether you are going to be falling through a glass window or a glass floor, because you can’t see...everything is just all the same.”

(Person with dementia talking about their local shopping mall)

This person went onto tell us how he no longer feels confident to visit the mall alone, and will only visit if accompanied by someone else. This limits their opportunity to visit as often as they would like, thus, impacting on their independence.

Another participant spoke of how she found the floor surfaces in all of Christchurch’s shopping malls potentially dangerous.

Dark coloured floor mats at the entrance to a doorway may be interpreted as a hole, again inciting fears of falling into it by some people with dementia. Other people with dementia have told us of the difficulty they encounter where black and white floor surfaces are utilised.

Large, multiple mirrors can make their world feel significantly more crowded and overwhelming than it probably already is. A person with dementia once told us that a small shop full with 10 people can feel like 100 people in his world. A further point about mirrors is that some people with dementia are no longer able to recognise themselves and may interpret the person they are seeing in their reflection as an intruder.

Other people with dementia have since told us of the difficulty they encounter where black and white floor surfaces are utilised.

One participant spoke positively about their local burger restaurant, referring to the use of space, colour and overall design:

“...there is room...you don’t feel like you’re cluttered up, you know. You can sort of eat free again. It’s good, dark colouring, and it’s not overly slippery and it’s not shiny...it’s tiled...but it’s not a tile that seems to gleam at you...nice clean toilets. Well looked after, but you have to look to find them.”

Good Dementia-friendly design checklist:

Signage:

- Signs should be clear, in bold typeface with good contrast between text and background
- There should be a contrast between the sign and the surface it is mounted on.
- Signs should be fixed to the doors they refer to – not on adjacent surfaces.
- Signs should be at eye level and well-lit.
- The use of highly stylised or abstract images or icons as representations on signage should be avoided.
- Think about placing signs at key decision points for someone who is trying to navigate your premises for the first time.
- Signs for toilets and exits are particularly important.
- Ensure that glass doors are clearly marked.

Lighting:

- Entrances should be well-lit and make as much use of natural light as possible.
- Pools of bright light and deep shadows should be avoided.

Flooring:

- Avoid highly reflective and slippery floor surfaces.
- Changes in floor finish should be flush.

Seating:

- In larger premises a seating area especially in areas where people are waiting can be a big help.
- People with dementia prefer seating that looks like seating – so for example a wooden bench rather than an abstract metal Z-shaped bench.

Navigation:

- Research shows that people with dementia use landmarks to navigate their way around, both inside and outside. The more attractive and interesting the landmark (which could be a painting, or a plant) the easier it is to use as a landmark.

(Taken from The UK Government Association Report entitled “Developing Dementia-Friendly Communities: Learning and Guidance for Local Authorities”, UK Government Association, 2014).

Given that Christchurch has lost so many of its iconic landmarks an idea might be to place model replicas at corresponding locations as a way of inciting fond memories for both people with dementia and other members of the community alike. This may also serve as a way of

informing national and international visitors about Christchurch's proud history.

NB: Information regarding guidelines on Age-Friendly Cities can be found at:
http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf

Section 6: Transport

Comments about transport services in and around Christchurch received mixed opinion. While some participants spoke of a friendly, supportive bus service others were less than impressed.

Difficulties cited by our participants included:

- Bus driver's failing to lower the bus to enable easy access where mobility was an issue – especially for people using walking aids
- Children failing to give up their seat for an older person, and bus drivers failing to request them to do so
- Bus drivers not allowing enough time for a person to get seated before moving
- Cold, exposed bus shelters with no seating available

One participant spoke of how the whole of process of using the bus service to get across the city has become much more problematic following the February 2011 earthquake. As a result, they now frequent their local shopping mall instead of going into the city centre or other areas of Christchurch.

What participants found most helpful were bus drivers who not only lowered the bus to enable easy access but those who would load their walking aids for them as well.

The UK has been instrumental in establishing ways to provide better, well-informed public transport



systems, with a number of transport providers taking steps to educate bus and train drivers about dementia. For example, bus drivers in Northumberland will soon be expected to complete a dementia-awareness component as part of their Certificate of Professional Competency (Alzheimer's Society, 2013).

Transport services in Canada have provided a unique design in bus shelters, which are not only enclosed but feature swings as seats to provide stimulation and enjoyment while people await the bus. Some can also be found in and around London, England.



A bus shelter in Montreal, Canada

Christchurch taxi services received lots of positive feedback. Many participants told us how taxi drivers will assist them to take their shopping bags to their front door.

All of those who used taxi services were very appreciative of the Total Mobility half price taxi vouchers, issued to anyone with a diagnosis of dementia.

Where a participant continued to drive their own car there was a general acceptance of the current road conditions in and around Christchurch amid the quakes, with one participant telling us of her gratitude at the timely manner in which roads were being repaired.

However, one participant commented on their confusion around the recent colour change to some local road signs from blue to green and the inconsistency across the city.

Checklist for Transport Providers:

- Bus/taxi drivers should smile and make eye contact with passengers.
- All transport providers should recognise when a person requires assistance, e.g. with walking aids.
- Bus drivers should lower the bus where possible to aid easy access for a person with dementia. Be mindful that they may not present with an obvious physical disability but may present with problems around spatial awareness and judgement.

- Bus drivers should allow people time to sit down before pulling away.
- Bus/train shelters/taxi ranks should provide adequate shelter from adverse weather conditions.
- All service providers, including those working in town/city planning, should ensure all signage is clear, contrasting (preferably black writing in lower case on either a white or yellow background) and consistent, making it easily recognisable.

Section 7: Access to Information

Much has been played out in the media of late about the need for people with dementia to receive a timely diagnosis and the potential consequences for patients and their support people who fail to seek a diagnosis (Phillips, Pond and Goode, 2011). However, upon receiving a diagnosis many people with dementia, along with their support people, report being left to deal with the consequences alone, with nobody advising them on how to access appropriate support or information services.

Being advised on what services and support networks are available, whether they are needed now or in the future, is paramount for ensuring a person's dementia journey is as smooth and as trouble-free as possible.

Legal advice around issues such as driving with a diagnosis of dementia and Enduring Power of Attorney (EPOA) can help a person with dementia and their support people to plan ahead. This can ensure that the person's chosen advocates are in place to act in the best interests of the person with dementia when the time arises that they no longer have the capacity to make sound decisions.

Upon receiving a diagnosis of dementia, and receiving no practical advice from her GP, one participant had sought a counsellor. She told us,

“She certainly didn’t pick up on any problems that I had. She just said to me “Oh well, just go away and think nice thoughts”. It just ... I just went away and I thought ‘Well, no point in going back to see her’. She just wouldn’t be able to understand my situation.”

(Person with dementia)

This person went onto tell us how when she was finally allocated a Needs Assessor, she was offered support with shopping and that it could be arranged so that someone would ensure her property was safe and secure before she went to bed. However, this person was still able to drive, do her own shopping and secure her property herself. What she actually wanted was sound advice on preparing for her future but this was not offered or provided.



GP consultation times are limited and, upon receiving a diagnosis of dementia, a person and/or their support person may have many questions, as well as wanting to address their emotional needs at such a time.

Some GPs will hand out resource packs for organisations including the Alzheimer's Association and Age Concern, which of course, is extremely

valuable. Yet, even this first step to accessing information can prove difficult for some people with dementia.

A pilot study has been carried out in memory clinics across the UK whereby Mental Health Nurse Practitioners have been supporting GPs with dementia diagnoses, treatment and advice. This has enabled people to access information in a timely manner upon receiving a diagnosis of dementia and has proven to be an invaluable service.

As previously discussed in Section 4, the internet is becoming increasingly popular among older people. Several of our participants described themselves as regular users, with one of them accessing his local Alzheimer's Association branch upon receiving a diagnosis of dementia:

"I have always had a bad memory so and then they diagnosed...Alzheimer's [disease], got in touch with Alzheimer's group here in Christchurch and learnt all about it, ah, read extensively on it and on the computer and everything. My wife has, too, and we have just seemed to cope well with it, I think."

(Person with dementia)

Social networking sites, such as "Facebook" and "Grown-ups" are gaining more popularity, with organisations including the Motor Neurone Disease Association now having their own Facebook page.

Key Points:

- The clinician making the initial diagnosis of dementia should ensure the individual concerned, and their support people, are provided with an opportunity to ask questions and seek support as early as possible, preferably within the clinic.
- Information about dementia and service provision needs to be available in a range of formats that are easily accessible and comprehensive.
- Needs Assessors/counsellors/advisors need to listen to the person with dementia to determine what advice, information or support they are seeking at any given time. Leave your contact details with them and/or their support person so they know how to get in touch when the need arises.

Section 8: Leisure

An active and socially interactive lifestyle has been found to improve quality of life and delay the onset of some dementias (Fratiglioni, Paillard-Borg, Winblad, 2004). Having an opportunity to participate in leisure activities was high on the list of priorities for almost all of our participants. Yet, many felt that this had been lacking since they developed dementia.



A significant number of people we interviewed spoke of wanting to continue playing golf but had stopped once they became aware of being much slower than they used to be.

Self-consciousness and a fear of being a hindrance to others are just some of the reasons behind a person's decision to cease participating in leisure activities. Others report feeling overwhelmed, especially in noisy, crowded environments.

We were told by one of our participants how he had stopped attending rugby matches as he found the whole process too overwhelming, from walking from the car park in busy crowds, to the noisy environment and the feeling of being "penned in" whilst seated in the stands.

Many of our sports stadiums here in New Zealand have private boxes available for group use, so it could be argued there are no reasons why

one of these could not become a designated box for people with dementia, with disability parking located nearby.

This then begs the question “does dementia prevent a person from participating in leisure activities? Or do providers of leisure services and facilities fail to recognize and support people with dementia to maintain their involvement?”

One participant told us how he used to enjoy going fishing. However, visual impairment now prevents him from doing so. We asked him, if someone were to provide chartered fishing trips, specifically developed for people with dementia, with suitably trained support staff available, would he participate? He told us in no uncertain terms that he would.

Another participant told us how he used to enjoy playing lawn bowls but lack of transport, shyness, and someone to accompany him are reasons for his inability to participate any longer.

New Zealanders are renowned for their love of sport and leisure pursuits. This is also one of the many reasons why the country attracts numerous international visitors and, increasingly, more migrants.

A common misconception of people living with dementia is that they are not able to learn new tasks and are reluctant to try new activities. This is not the case as one of our participants was quick to point out.

Case Study

Participant H has a diagnosis of Vascular Dementia. He lives independently in his own home and recently retired. He describes himself as a “loner”, therefore, has no desire to join a social group. He enjoys being outdoors and would really like an opportunity to try his hand at horse riding. However, there are currently no horse riding or pony trekking services provided for people with dementia in or around Christchurch.

Measures are finally been taken around the world to not only acknowledge but to support people with dementia to maintain their quality of life. This includes empowering them to continue to enjoy many of the activities that give them a sense of purpose and fulfilment.

Our findings reveal that there are some people living with dementia in Christchurch who would like to try horse riding, while others would like support to take up fishing once more. There are also numerous people who would like an opportunity to play golf or bowls at a pace that meets their current level of ability without feeling intimidated or as though they might be a burden to other players.

Here in New Zealand Alzheimer's Canterbury and Alzheimer's Auckland have established links with local golf courses where designated days and times have been awarded to people with dementia.

An art appreciation group called “Artzheimer's” has been established in Christchurch based on the New York model, which allows people time to reflect, discuss and share their own interpretations to various art works. Indeed, one of our participants spoke of her enjoyment of this activity.

A gymnasium in Hamilton has designated two mornings per week for people from the Parkinson's Association. This has come as a welcome addition for both people with Parkinson's disease and the operators as this service is being offered at times when the gymnasium would otherwise be less occupied. There is an opportunity, not only for this gymnasium but others around New Zealand, to extend this service to people with dementia, especially since current research indicates how physical exercise can reduce the rate of onset.

Several years ago an organisation called "Dementia Adventure" was established in the UK amid calls from people with dementia asking for activities programmes that they found enjoyable and met their needs – activities that were not provided by day centres. One of these activities was sailing.

Concerns were raised about safety but as the organisation's director, Neil Mapes, speaking at the annual International Dementia Conference in 2012 was keen to point out, the participants were fully competent to pursue this activity as they had been doing so for many years.

Dementia Adventure (2013) recognises the importance of outdoor space for all people living with dementia and offers many other activities, including woodland walks and nature holidays.

Other activities that participants would like to recommence should they become available for people with dementia included ballroom dancing – even if it was simply to watch others dance, attending a cricket match, a Do-It-Yourself group, and swimming (no public pool available in Sumner).

One participant who resided in a dementia rest home told us she would like an opportunity to visit Christchurch Botanic Gardens. She went onto

to tell us that her facility provides a weekly shopping trip but this was the only outdoor activity available.

Key Points

Having a diagnosis of dementia should not serve as a barrier to enjoyment, pleasure and engagement in leisure activities. Leisure service providers need to think more creatively about ways they could be more inclusive of people with dementia. This might include:

- Providing quieter spectator areas in sports stadiums allowing access to only a small number of people. Also allow access to disability parking.
- Offering designated days and times to people with dementia for activities such as golf, bowls, fitness and dance. This could be in conjunction with organisations such as the Alzheimer's Association, the Huntington's Disease Association and the Parkinson's Disease Association.
- Recruit personnel or request volunteers with experience of having worked with people with dementia, or people with dementia who have the knowledge, skills and ability to support others.

Section 9: Outdoor Environments

Access to outdoor environments has a huge bearing on the physical and emotional well-being of people with dementia. Moreover, being denied access has been associated with depression and increased agitation (Duggan, Blackman, Martyr and van Shaik, 2008).



Almost all of the participants in our study cited having an opportunity to access outdoor environments and be included as part of their community as the most important feature in their lives. This included people living in care facilities. Being in touch with nature was highly valued.

One person told us that their greatest fear upon receiving a diagnosis of dementia is never been able to get outside again once they reach a point whereby they can no longer live independently.

Many people spoke favourably of Christchurch's Botanic Gardens. Some continued to frequent them while others were denied the opportunity to visit due to physical disabilities, or constraints and/or a lack of resources within their care facility.

One participant residing in a care facility mentioned how they would love to revisit his home town of New Brighton. They have many fond memories from their childhood and would like to be able to walk along the beach or sit on the pier.

When being asked what made their community a good place to live, one participant told us:

“Well, being able to see the hills, the number of tress. It is not a barren, concrete jungle, you know. You can see...you can almost see the country from wherever you are, can’t you?”

(Person with dementia)

As far as the Christchurch City rebuild is concerned people told us that they would like a city centre with lots of open spaces, plenty of trees and plants, and an environment replete with flowers and shrubs was something that they considered made for a pleasant community. Quiet spaces were also appreciated.

Many hoped for a modern city although one participant added that it would be nice to keep some of the old heritage buildings. However, they were unsure how they might fit in amongst the modern buildings.

There was a great appreciation for local parks and reserves, especially where there was an opportunity to see sports being played, but opinions about the streets were mixed. Some people stated that they liked to see the streets lined with trees while others found these hazardous and a nuisance (see Section 10).

“I think I would sooner be back in Ilam...It is more leafy and I do like leafy suburbs, there is no doubt about it.”

(Person with dementia)

Of those participants who also had a physical disability they expressed their gratitude to the support services that provided regular outings.

“...I think, if we didn’t have those outings it would be...pretty...pretty dull living here.”

(Person with dementia)

On being asked what would constitute a perfect day for them? They replied,

“Oh, I think just to be taken out somewhere. Really, have a cup of coffee or something, just to get into a different environment.”

(Person with dementia)

A number of research studies have all identified the importance having accessible outdoor spaces for people with dementia. While most dementia care facilities make every effort to provide fragrant, colourful, stimulating gardens not all allow for easy access. For some, this is due to building design where people with dementia reside above the ground floor. However, where this is the case, every effort should be made to ensure residents are supported to spend time in outdoor areas, both within the facility and within their community.

Other care facilities worry about safety risks and will, therefore, lock external access doors to communal gardens. Again, research tells us that the risk of falling and, consequently, sustaining an injury, is increased where freedom of movement is restricted for a person with dementia.

Support people also worry about a person's potential to become lost should they allow easy access to the outdoors within their own home. Enlisting the help of support services that provide daytrips and regular outings might be useful since boredom is largely associated with a person with dementia wanting to leave their home environment.

The weather conditions should not necessarily deter someone from going outside unless conditions are particularly hazardous. Raincoats, thermal layers, gum boots should be provided to allow for this. The person will let you know in whatever ways they are able to communicate if they do not wish to be outside. Bear in mind that even where the question is asked, a person may say "no" when in fact they might mean "yes". Furthermore, if an attempt proves fruitless, try again later or on another day. A person's mood may vary – just like the weather!

Where the likelihood of someone leaving their home unaccompanied, and there is a risk that the person may lose their way, tracking devices are now available that enable support people to locate the person with dementia more easily.

Key Points

- Opportunities to access outdoor areas are essential for most people with dementia.
- People with dementia generally prefer quiet, wide open spaces.
- An opportunity to be in touch with nature is often welcomed.
- Lots of varieties of plants and flowers provide sensory stimulation.
- Most people would like to see a modern Christchurch for the future.



Section 10: Safety

Throughout this report we have made reference to how many of the symptoms associated with dementia can invoke feelings of fear and frustration for the person living with dementia. Whether this is related to a fear of falling, a fear of perceived intruders, fear of being taken advantage of, or a general fear of what the future may hold. Such feelings are usually borne out of an overall sense that they are losing control of their own lives. Therefore, it is imperative that every member of every community worldwide strives to provide an environment that promotes personal safety, with people displaying positive attitudes towards, and awareness of the needs of people with dementia if we are to create a truly dementia-friendly society.

People with dementia told us that they want to live in a community whereby:

- they know their neighbours
- where people understand their needs and do not try to “trick” them
- there is good, clear signage that facilitates them to navigate their way around independently
- there is a visible police presence
- traffic is limited in residential areas and there are more cul-de-sacs being developed as part of the Christchurch rebuild
- safe crossing points and pedestrian crossings activated by traffic lights rather than zebra crossings or pedestrian crossing islands were made available on busy streets

- there are unnecessary hazards lining the streets and footpaths – e.g. avoid planting large trees that cause the roots to uplift the pavements making them uneven and hazardous

In the aftermath of the 2010/2011 Christchurch earthquakes examples of strong neighbourhood support began to emerge, not least with the ingenious idea of then university student, Sam Johnson, who developed the internationally acclaimed “Student Army”. This consisted of a group of young student volunteers from the University of Canterbury who embarked on supporting people in and around Christchurch to deal with the devastation, namely on a practical level, such as clearing away liquefaction, which had entered the homes of many and created disruption on the streets. It was extended to include other members of the community who were also willing to assist in the clean-up operation.

Neighbourhood Watch schemes have been in place in some communities for a number of years and consist of neighbourhoods taking a resilient approach to potential crime by monitoring suspicious, potentially criminal activity.

In 2014 Christchurch City Council introduced “Neighbourhood Week” to encourage local communities to come together and host street parties and sporting events.

In accordance with health and safety and accessibility, New York’s Department of Transportation (2013) has issued a document entitled the “Street Design Manual”. This is a comprehensive manual that gives a variety of recommendations for safe, effective, practical street design that encompasses roadways and sidewalks, traffic calming, materials – e.g. pavement surfaces, lighting, furniture and landscape. Of relevance to the issue of dangerous tree roots as mentioned by one of our participants are rubber pavement tiles. These can be cut to shape around trees, they are thinner to allow for tree roots to grow, are

permeable, helping to reduce condensation and thus reducing the risk of fracturing and upheaval. Furthermore, being rubber, they may help to reduce injuries do require regular maintenance. Before resorting to using this type of material it might be worth finding out how appropriate it is for those people who present with a shuffling gait, for instance, those with Parkinson's dementia or Dementia with Lewy Bodies as it could prove problematic.

We referred to floor surfaces in Section 5 and discussed how black and white contrasting coloured floor surfaces can be confusing and difficult to navigate for some people with dementia as the black sections can be misinterpreted as holes. This is particularly poignant in the case of zebra crossings. Some people have been known to leap from one white section to the other for fear of falling into a black hole, yet New York's Department of Transportation has failed to recognise or acknowledge this factor as many of the city's newly developed streets feature multiple zebra crossings.

Although many streets in the UK continue to feature zebra crossings, even among new developments, a relatively recent type of pedestrian crossing is the Puffin crossing (NI Direct, 2013). This has been designed to allow pedestrians more time to cross the road as sensors prevent traffic from being able to proceed until the pedestrian has finished crossing, gives instructions where pedestrians will be standing waiting to cross making them more visible for those with partial visual impairments, and avoids the use of contrasting surface colours that prove problematic for some people with dementia.

Safe crossing points are an essential requirement for all pedestrians, especially people with a disability or who may be slow or hesitant. People with dementia frequently report feeling like their world is moving much faster than it actually is, therefore, traffic moving at 50km/per hour

can be perceived as travelling much faster, thus, inciting feelings of fear and insecurity.

Some people with dementia continue to ride a bicycle. Speaking at a recent event in Auckland one person with dementia told of how he would recommend that all cycle lanes are painted lime green as this helps a person with dementia to decipher the pavement from the road.

Key Points

- People with dementia need to be given plenty of time and space when navigating their environment. Providing safe pedestrian crossing points that allow them time and are easy to comprehend (avoid zebra crossings as far as possible as dementia can alter a person's perception).
- Traffic calming measures and cul-de-sacs/no exit residential streets will support people with dementia to feel safe in their community.
- Neighbourhood schemes, such as Christchurch's annual "Neighbourhood Week" may support people with dementia to get to know their neighbours, and for their neighbours to get to know them. These may need to occur more frequently to be effective.
- Street design, and the materials used, is imperative for ensuring personal safety for people with dementia. It is important to consider pavement materials, especially where tree roots may force pavements to crack and protrude, making mobility more difficult and increasing the risk of accidents.



Summary

There are numerous ways in which communities around the world can work towards becoming dementia-friendly and not all need be costly. As we have identified in this report education and awareness about dementia and the implications for those affected by it serves as an essential starting point. Without some level of understanding of the lived reality for a person with dementia we cannot possibly provide services that meet their needs. Of course, it is important to bear in mind that the most effective way to learn about dementia is to work in partnership with people with dementia. They are “the experts” after all.

The way we interact with people with dementia can have a huge bearing on their quality of life. Failure to recognise when a person is struggling to comprehend the spoken word or navigate the physical environment can result in them ceasing to be part of their community due to embarrassment or fear. Hence, this can lead to withdrawal and social isolation, which in turn, can increase the rate of disease progression.

The physical environment is crucial for ensuring people with dementia are facilitated to maximise their independence for as long as, and as far as possible. This is where Christchurch is in a unique position right now amid the aftermath of the 2010/11 earthquakes. Designers, architects, technicians, city planners and everyone else involved in the city’s redevelopment have the potential to make Christchurch the very first designed and built dementia-friendly city in the world. Again, it is imperative that all personnel consult “the experts” before progressing with their ideas.

Providing a vast range of accessible, relatively inexpensive, leisure services for people with dementia, or more importantly that people with dementia can be included in, can vastly improve their quality of life and potentially slow the rate of disease progression. In addition, relationships with family and support people can be maintained, lessening any carer-stress and decreasing the economic impact on the

nation as the person with dementia would be able to continue living in their own home for longer.

People with dementia have identified that it is vital they have continued access to outdoor space, familiar places (where possible) and to be connected with their community, regardless of whether they reside in their own home or in a care facility. Providers of care and support services need to recognise this and ensure they have the resources required to implement outdoor activities beyond the facility grounds as part of planned care. Only then can they be seen to be delivering truly person-centred care.

As we outlined at the beginning of this report a dementia-friendly model encompasses the needs of just about every member of society. This includes families with young children, people with a range of physical disabilities and mental health problems, along with international visitors and migrants for who English is not a first language as a dementia-friendly model places a huge emphasis on pictorial signage and use of simple language. A dementia-friendly model also harbours physical and psychological safety.

By adopting this model Christchurch opens itself up to a number of additional benefits. Presenting itself as a world leader in the development of dementia-friendly communities has the potential to generate global interest leading to an increase in tourism and economic growth, recruit new and retain existing innovators in design, technology, and service delivery, and create stronger, more inclusive communities.

Finally, a dementia-friendly Christchurch would not only serve to support its future generations but it would also provide the perfect way to say “Thank You” to all of those who have gone before, some of whom may have lost their lives in the devastating earthquakes. This is a one-time

only opportunity which, if not taken full advantage of, could prove far more costly in the future.

References

Alzheimer's Australia New South Wales (2011), Building Dementia and Age-Friendly Neighbourhoods,
<http://www.fightdementia.org.au/common/files/NSW/20110803-NSW-PUB-DementiaFriendlyNeighbourhoods.pdf> accessed 1 March 2013

Alzheimer Europe (2014), National Dementia Strategies (diagnosis, treatment and research), <http://www.alzheimer-europe.org/policy-in-practice2/Country-comparisons/National-Dementia-Strategies>, accessed 7 January 2014

Alzheimer's Disease International (2012), Dementia: A Public Health Priority,
http://www.who.int/mental_health/publications/dementia_report_2012/en/, accessed 1 March 2013

Alzheimer's Disease International (2014), Dementia and Risk Reduction,
<http://www.alz.co.uk/research/world-report-2014>, accessed 1 October 2014

Alzheimer's Society UK (2013), Dementia 2013: The Hidden Voice of Loneliness,
http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1677,
accessed 25/04/2013

Alzheimer's Society UK (2013), Building Dementia-Friendly Communities: A Priority for Everyone,
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1916,
accessed 14 November 2013

Anderson, J. (2013), Global Approaches to Dementia Care,
<http://www.aplaceformom.com/blog/dementia-care-around-the-world-4-2-2013/> accessed 22 August 2014

Bennett, D.A., Schneider, J.A., Tang, Y., Arnold, S.E. and Wilson, R.S. (2006), The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: a longitudinal cohort study, *Lancet Neurol*, Volume 5, pp. 406-12

Brorsson, A., Ohman, A., Lundberg, S. and Lygard, L. (2011), Accessibility in public space as perceived by people with Alzheimer's disease, *Dementia, Sage*, Volume 10 (4), pp. 507-602

Cantley, C. and Bowes, A. (2004), *Dementia and Social Inclusion: The Way Forward*, cited in Innes, A., Archibald, C. and Murphy, C. (2004), *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*, Jessica Kingsley Publications, London, Ch. 16, pp. 255-269.

Christchurch City Council (2014),
<http://www.ccc.govt.nz/cityleisure/eventsfestivals/communityevents/neighbourhoodweek/planningyourevent.aspx>, accessed 16 September 2014

Cobbam, N. (2004), Improving Domiciliary Care for people with dementia and their Carers: The Raising the Standard Project, cited in Innes, A., Archibald, C. and Murphy, C. (2004), *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*, Jessica Kingsley Publications, London, Ch. 3, pp. 50-66

Dementia Action Alliance (2010). National dementia declaration. London: DAA.

Dementia Adventure (2014), <http://www.dementiaadventure.co.uk/>, accessed March 2012

Dreaper, J (2012), Why bus drivers are being taught about dementia, E:\Dementia Friendly Communities\BBC News - Why bus drivers are being taught about dementia.mht (accessed 26 April 2013)

Duggan, S., Blackman, T., Martyr, A. and van Shaik, P. (2008), The Impact of Early Dementia on Outdoor Life, *Dementia*, Sage, Vol. 7, pp. 191-205

FactAlerts (2014), <http://www.factalerts.com/montreal-bus-stop-swings/>, accessed 12 September 2014

Fratiglioni, L., Paillard-Borg, S. and Winblad, B. (2004), An active and socially integrated lifestyle in late life might protect against dementia, *Lancet Neurol*, Vol. 3, pp. 343-53

Gee, S., Scott, M. and Croucher, M. (2013), Walking in Another's Shoes: Encouraging person-centred care through an experiential education programme, <http://akoaootearoa.ac.nz/ako-hub/good-practice-publication-grants-e-book/person-centred-care>, accessed 25/04/2013

Guisset-Martinez, M.J. (2012) Three Alzheimer plans in France (2008-2012), cited in Innes, A.; Kelly, F. And McCabe, L. Key issues in evolving dementia care: international theory-based policy and practice,

London, Jessica Kingsley, pp 122-136, taken from <http://www.alzheimer-europe.org/policy-in-practice2/Country-comparisons/National-Dementia-Strategies>

HammondCare (2011), Caring for People with Dementia in Hospital Settings, HammondPress, New South Wales, pp.6-7

Henley, J. (2012), The village where people have dementia – and fun, <http://www.theguardian.com/society/2012/aug/27/dementia-village-residents-have-fun>, accessed 6 January 2014

Hulko, W. (2009), From 'not a big deal' to 'hellish': Experiences of older people with dementia, *Journal of Aging Studies*, 23, pp. 131-144

Hughes, J. (2012), Society should embrace people with dementia, *Nursing Standard*, Vol. 26, No. 31, pp.26-27

Innes, A. and Sherlock, K. (2004), *Rural Communities*, cited in Innes, A., Archibald, C. and Murphy, C. (2004), *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*, Jessica Kingsley Publishers, London Ch. 2, pp. 32-49

Innovations in Dementia CIC (2011), www.innovationsindementia.org.uk, accessed 02/05/2013

Johnson, S. (2014), Wikipedia, [http://en.wikipedia.org/wiki/Sam_Johnson_\(activist\)](http://en.wikipedia.org/wiki/Sam_Johnson_(activist))

Kitwood, T. (1997), *Dementia Reconsidered: The person comes first*, Open University Press, Buckingham, Ch. 1, P. 8

Lahey, L. (2012), *Dementia Challenge*, *Practice Nursing*, Vol. 23, No. 9, p. 432

Lee, S. (2010), South Korea's 'war on dementia', *Canadian Nursing Home*, Vol. 21, No. 4, pp. 14-17

McColgan, G. (2004), *Images, Constructs, Theory and Method: Including the Narrative of Dementia*, cited in Innes, A., Archibald, C. and Murphy, C. (2004), *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*, Jessica Kingsley Publishers, London, Ch. 11, pp. 169-183.

Milton, S. (2012), What makes a dementia-friendly community? *The Journal of Dementia Care*, Vol. 20, No. 2, pp. 12-13

Mitchell, L. (2012), *Breaking New Ground: The Quest for Dementia Friendly Communities*, www.housinglin.org.uk, accessed 30/04/2013

NI Direct Government Services (2013), *Puffin Crossing*, <http://www.nidirect.gov.uk/puffin-crossing>, accessed 16 September 2014

NHS Education for Scotland, (2014) *Promoting Excellence in Supporting People through a Diagnosis of Dementia*, http://www.nes.scot.nhs.uk/media/2614737/supporting_people_through_a_diagnosis_of_dementia.pdf (accessed 22 August 2014)

New York City Department of Transportation (2013), Street Design Manual, www.nyc.gov/streetdesignmanual, accessed 20 January 2014

Penn, D. and Wykes, T. (2003), Stigma, Discrimination and Mental Illness, *Journal of Mental Health*, 12 (3), pp. 203-208

Phillips, J., Pond, D. and Goode, S.M. (2011), Timely Diagnosis of Dementia: Can we do better?, *Alzheimer's Australia*, https://fightdementia.org.au/sites/default/files/Timely_Diagnosis_Can_we_do_better.pdf, accessed 13 October 2014

Saad, K. (2012), Prime Minister's Challenge – Intergenerational School's Project, <http://www.worcester.ac.uk/discover/dementia-prime-ministers-challenge-intergenerational>, accessed 02/05/2013

School of Nursing and Midwifery – Trinity College Dublin, Perceptions of Stigma in Dementia: An Exploratory Study, <http://www.alzheimer.ie/Alzheimer/media/SiteMedia/PDF's/Research/Stigma-in-Dementia-Report.pdf?ext=.pdf>, accessed 15 January 2014

Stirling City Council (2013), Dementia-Friendly Stirling, <http://minutes.stirling.gov.uk/pdfs/socialcare%26health/Reports/SH20140313Item11DementiaFriendly.pdf>, accessed October 2013

UK Government (2009), Living Well with Dementia: A National Dementia Strategy, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf, accessed 3 April 2012

UK Government (2013), G8 Summit Dementia Declaration,
<https://www.gov.uk/government/publications/g8-dementia-summit-agreements>, accessed 15 December 2013

Young Dementia UK (2014), Types of Dementia in Younger People,
<http://www.youngdementiauk.org/types-dementia-younger-people-0>,
accessed 7 October 2014